

Caring for those with Parkinson's
Disease:
The Effect of Social Networks on the
Family Carer's Role

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*To know who we are, we must understand how we are
connected.*

Nicholas A. Christakis and James H. Fowler (2009, p xiii)

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Abstract

This study explored the social networks of informal carers for those with Parkinson's Disease and how these impacted on their caring role. An increasing ageing population in the UK means that demand for informal care is growing. Family carers are therefore providing greater amounts of care against a backdrop of social change with smaller, more diverse family structures and diminishing public sector resources.

A case study design was used with 20 carers who were recruited through Parkinson's UK. Social network data, carer diaries and interviews acted as complementary data collection methods. The diary-interview method alongside visualisation of the network sociograms at interview offered a valuable means of developing and exploring the data with the carer. Individual case and cross case analyses were undertaken using the Framework Method. An in-depth view of the carers' networks was possible, that uncovered the structural features, and the detailed intricate practices and interactions that occurred in relation to the caring role. Using network approaches and a Bourdieusian lens, the findings demonstrated that the carers are uniquely positioned in relation to their Personal Community (the informal sector), and the state and the market as the providers of formal health and social care. Third Sector Organisations were viewed as a '*lifeline*' by the carers with the support offered through these groups acting synergistically with the formal care sector. As the care trajectory progressed the carers increasingly acted as network bridges, brokers, and co-ordinators as they navigated and negotiated across the various networks of care. The carers engaged in a complex series of transactional processes to access assistance and support through bonding, bridging, and linking social capital whilst also drawing on other personal resources of economic and cultural health capital. Trust, reciprocity, mutuality, and carer recognition acted as facilitators of support, whereas tensions, conflict and ambivalence arose when expectations of support and recognition were lacking. This study has given new insights into the evolving networks of those caring for a family member with Parkinson's Disease. Co-ordinating these networks through navigation and negotiation is complex and forms part of the 'work' of care. The findings can inform the practice of health and social care professionals to aid carer recognition, assessment, and partnership working.

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Abbreviations:

ADASS	Association of Directors of Adults Social Services
ADL	Activities of Daily Living
CQC	Care Quality Commission
DP	Direct Payments
DWP	Department of Work and Pensions
ISW	Information Support Worker
LA	Local Authority
NAO	National Audit Office
NGO	Non-Governmental Organisation
NICE	National Institute for Health & Care Excellence
ONS	Office for National Statistics
PD	Parkinson's Disease
PHE	Public Health England
POPSS	Partnership for Older People Projects
PSSRU	Personal Social Services Research Unit.
TSO	Third Sector Organisation
VCO	Voluntary Community Organisation

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Chapter 1: Introduction

1.1 Background

Within the UK, the increasing ageing population with an associated increase in those with long term conditions, means that demand for informal care is growing (Department of Work & Pensions, 2020; Office for National Statistics (ONS, 2014). With an increased demand for both informal (unpaid), and formal care provision, and as demand exceeds supply, a looming 'care gap' has been forecast (Pickard, 2015). However, austerity measures, and shortages in the health and social care workforce, mean that the relative provision of formal care is also shrinking with increasing concerns about the sustainability of adult social care (Associate of Directors of Adult Social Services, (ADASS), 2018; Brimblecombe et al., 2018; Glendinning, 2012; Humphries et al.), 2016; National Audit Office (NAO), 2016, 2018a; Pickard, 2015). Informal (unpaid) family carers are therefore providing increasing amounts of care (ONS, 2017). This is also against a backdrop of social change. More older people are living alone, with families living further apart and smaller, more diverse family structures (Silverstein & Giarrusso, 2010). Women, who have formed the biggest proportion of informal carers, are now more prevalent in the workforce which is altering the numbers available for support (Colombo, Llena-Nozal, Mercier, & Tjadens, 2011; Pickard, 2015). Furthermore, the propensity and disposition to care by future generations is also questioned (Silverstein and Giarrusso, 2010).

The evolution of family structures and the changing landscape of care in the formal sector means that further empirical work is needed to examine care provision beyond the carer/care-recipient dyad. Contemporary families are 'characterised by a complex web of relationships' that are more than those situated within the boundaries of the household (Widmer et al., 2013, p. 28) The finer detail of how the wider family and/or friends contribute to and supports or aids the carer in their role is less well documented (Broese van Groenou & De Boer, 2016; Roberto & Blieszner, 2015; Sims-Gould & Martin Matthews, 2007). Furthermore, the relationships and dynamics that are part of both traditional and pluralistic families and close friends have not been a particular

focus of the carer network (Keating & Eales, 2017; Lapierre & Keating, 2013). The changing relationship of carers with formal care providers and the increasing provision from Third Sector Organisations (TSOs)¹ is also another aspect of the carer's network that warrants further study (Charlesworth et al., 2007; Kemp et al., 2013; Moen & DePasquale, 2017).

1.2 Social Capital and the Social Networks of Carers

Carers are situated in an array of social relations that have the potential to support and assist the carer in their role (Jacobs et al., 2018; Keating & Dosman, 2009; Keating et al., 2005; Rutherford et al., 2014; Sims-Gould & Martin Matthews, 2007). The resources and associated dynamics of these social relationships can offer positive benefits that can aid those in the network. Bourdieu defined this resource as *social capital*:

[it] is the sum of resources, actual or virtual, that accrue to an individual or group by virtue of possessing a durable network of more or less institutionalised relationships of mutual acquaintance and recognition (Bourdieu & Wacquant, 1992, p. 119)

The social capital and social networks of older people have been examined in light of changing demographics and on-going shifts in social policy (Bowling et al., 1991; , 2009a; Keating & Dosman, 2009; Roth, 2020; Vassilev et al., 2011; Wenger, 1997). This literature has demonstrated the positive effects of social capital and the supportive functions of integrated social networks. However, the fragility of older people's networks has also been demonstrated with recognised difficulties in adapting to the transitions and turning points encountered in older age and ill health (Egdell,

¹ Third Sector Organisations (TSOs) is a term used to describe the range of organisations that are neither public sector nor private sector. It includes voluntary and community organisations (both registered charities and other organisations such as associations, self-help groups and community groups), social enterprises, mutuals and co-operatives (NAO, 2013)

2012a; 2012b; Egdell, et al., 2010; Phillipson, 2001; Wenger, 1997). Drawing on social network theory and the concept of social capital this study will examine the social networks of carers of those with Parkinson's Disease (PD). It will explore the form and function of these networks and how they are utilised in the caring role.

1.3 Demographic Change and the Demands for Care

The ageing population and associated longevity have not been matched by increases in a healthy life expectancy. Thus, because of these changing demographics, it is known that the numbers with long term conditions and disabilities requiring care are increasing and have greater health and social care needs (Marmot, 2010; Marmot, 2020). The support of individuals as they age with disabilities relies on the informal care of family and friends. The significant numbers required to provide informal care have been recognised for some time (Beesley, 2006; Buckner & Yeandle, 2011; Pickard, 2008: 2015; Wanless, 2006). Almost 20 years ago it was estimated that an increase in informal care of over 50% would be needed by 2026 compared to levels in 2003 (Wanless, 2006).

In 2011 the Census data indicated that there were 5.4 million carers in England (ONS, 2011). Of these 1.3 million were providing over 50 hours of care per week. However, the numbers of carers can differ across studies and is dependent on the focus used, i.e., from a care-recipient or carer perspective, to quantify this. More recent ONS (2017) data indicates that 8% of the UK's private households were unpaid carers for someone during the 2015-2016 financial year. The figures also indicate that these carers are predominantly women (59%). In terms of employment, only half of adult carers were employed either part-time or full-time. Nearly a third (29%) said they spent 35 hours or more a week as an informal carer. For both men and women aged over 50, there has been an increase in the time devoted to unpaid caring of adults by 15% and 21% respectively between 2000 and 2015. Data from the Family Resource Survey for 2018-2019 (Department of Work and Pensions (DWP), 2020) found that parents were the main recipients of informal care and 34% of informal carers, cared for a parent outside of their own household. Carers UK (2019) estimated that there may be as many as 7.3 million adult carers in England equating to 1 in 6 of the adult population.

In 2015 Carers UK valued carers' contribution to the economy at £132 billion per year (Carers UK, 2015)². This has not only significant financial implications in terms of the sustainability of the NHS and social care but also has a wider impact on society. The role of these carers in helping to maintain a good quality of life for individuals in the community is recognised as significant (Commission of the European Communities, 2005). Although over the last three decades the role of carers has been part of several policy agendas and statute, (see Table 1 for a full summary), carers still feel that their role is often unrecognised, and their needs are overlooked (Carers UK, 2004, 2015, 2019). Carers often have poorer health, suffer financial hardships are more socially isolated, with their family, social and working lives affected by their caring role (Carers UK, 2010; Hirst, 2004; Wanless, 2006). Thus, successive Governments have recognised that more is needed to identify, engage, and support carers utilising a range of resources and flexible approaches (Yeandle & Wigfield, 2011).

1.4 Parkinson's Disease: An Overview

PD falls within the category of a long-term condition. It is the second most common neuro-degenerative condition, predominantly occurring in later life (Parkinson's UK, 2020) and causing increasing morbidity and dependency as the disease progresses. PD can lead to significant physical and cognitive decline. It is currently incurable, and the incidence rises sharply with age, with a median age of onset of 60 years (Jankovic, 2008). The disease can have a protracted course, with duration of illness from diagnosis of 15-20 years. The progression of PD is such that it often requires the support of an informal carer. The role of the PD carer is important in supporting disease management and the activities of daily living (Vatter et al., 2018). Caring for somebody with PD can be challenging and requires a balancing of personal and care-related responsibilities (Solimeo, 2009; Williamson et al., 2008). The profile of informal carers of those with moderate to advanced PD has been examined in a UK study (Hand et al., 2019). The mean age of the carers was 70.7 years and 66% were female, caring

² This was based on a calculation that applied the official cost of replacement care at that time to the number of hours carers spent providing care and an estimate of the number of carers projected from the 2011 Census data

for a median of 16 hours/day. The majority (80%) provided support with housework and acted as companions, almost two thirds helped with dressing and nearly half with feeding. Within this group of carers there was a significant relationship between the stage of the disease and the level of need, with increasing carer strain and a reduction in the carers' quality of life. Similar findings have also been noted by (Martínez-Martín et al., 2007). In Chapter 2 a more detailed review will be given in relation to the context and challenges associated with PD.

1.5 Introducing the Concept of Care

Care and caring are an important aspect of human relationships and can be considered as a normative activity. Caring can be viewed as having both an affective dimension 'caring about' and a practical or instrumental dimension in 'caring for' (Ungerson, 1983, p. 31). Previously, there was a dichotomous view of the carer and the care-recipient relationship, with an emphasis on dependency and caregiving (Fine & Glendinning, 2005), with those receiving care having very different needs and interests to those providing care (Lloyd, 2000, 2006). However, the process of care is a dynamic one in which the carer and care-recipient's individual, relational and contextual factors are bound together and interdependent (Connidis & Barnett, 2019; Corden & Hirst, 2011; Nolan et al., 2004)

1.5.1 Defining the Term 'Carer'

The term carer is the most often used and most widely understood. The term is not always recognised by those who care themselves since care is often provided in a family context and falls within normative views of family responsibilities and expectations (Barnes, 2012; Cavaye, 2006; Connidis & Barnett, 2019; Finch & Mason, 1993; Twigg & Atkin, 1994). Molyneaux et al., have argued that there is 'a consistent failure of the term 'carer' as a recognisable and valid description of the relationship between 'carers ' and those for whom they care' (Molyneaux et al., 2010, p. 422). Lloyd (2000, 2006) has also cautioned on using the term, since in focussing on one part of the caring relationship can be divisive to the relationship and disempowering to the

care recipient. For this work the term 'carer' will be used throughout to refer to people who provide unpaid care to adults. The ONS (2011) when collecting the Census data defined a person as a provider of unpaid care;

... if they looked after or gave any help or support to family members, friends, neighbours or others because of long-term physical or mental ill health or disability, or problems related to old age. (ONS, 2011)

In some studies, the term 'informal' is used in relation to those carers not in receipt of payment and 'formal' in terms of those who receive payment as employees. It is important to distinguish carers from people who are employed in health or social care and are paid to provide regular care and support since most issues that affect these groups are quite distinct (Barnes, 2012; Henwood et al.,2017). In the last 10 years much of the demographic data provided and analysed in terms of carers within the United Kingdom has been based on the ONS figures from the 2011 Census. Therefore, use of this definition allowed a consistency when examining much of the national evidence in relation to carers and is comprehensive in terms of the reasons that individuals may require care and support.

During the course of this Doctorate the Care Act (2014: 10 (3)) has now defined the term carer as follows: *'Carer' means an adult who provides or intends to provide care for another adult (an 'adult needing care');* however the following caveats are included in subsection 9: *An adult is not to be regarded as a carer if the adult provides or intends to provide care—(a)under or by virtue of a contract, or (b)as voluntary work.* Although this definition is significant, since it is enshrined in legislation, and is a specific definition for the purpose of assessment and eligibility for services, resources, and financial benefits, the ONS gives a broader sense of the term carer and has been a working definition throughout the course of this study.

1.6 The Policy Context: Shifting Care Provision and the Emphasis on Care in the Community

In the last 30 years there have been significant policy developments in relation to carers as their role in society has been increasingly recognised and acknowledged. The political focus on carers has been accentuated as radical health and social care reforms have taken place. Since the 1960s Government policy has moved towards greater care in the community away from the facility-based hospital settings. This approach accelerated in the 1980s as part of the hospital closure programme. During the 1990s and into the millennium these changes continued as successive Governments pursued health and social care policies that led to a significant shift to a mixed economy of care (Klein, 1995). This entailed the withdrawal of Local Authorities (LA's) and the NHS from the direct provision of long-term care and resulted in major changes to adult social care policy and its provision. Community care was viewed as preferential to that of institutional care and most importantly the most economical (Twigg, and Atkin, 1994). The neo-liberal policies followed by the Conservative Governments from 1979 included a focus on markets and managerialism, particularly in relation to the public sector. This was viewed as a means of cost effectiveness reducing inefficiencies and waste. 'Marketisation' of the health and social care system also became a fundamental aspect of reform (Klein, 1995). Thus, the principles of the market (private) sector would be applied to the public sector in terms of administration and the concept of competition. This approach continued during the Labour administration of 1997-2010 and the subsequent Coalition and Conservative Governments since 2010 (Klein, 2019).

1.6.1 The Policy Context: Carers' Rights and Recognition.

The separation of social care and the NHS (from the founding of the NHS in 1946 and the repeal of the Poor Law in 1948) led to legislation and a requirement by social care providers, to provide for disabled people, older people, children, and carers. In the 1960s and 1970s the United Kingdom first began to recognise carers in national policy in terms of taxation and income support through the introduction of the Invalid Care Allowance in 1975. The campaigns on carers' issues by Carers UK and other Non-Governmental Organisations (NGOs) over a significant period ensured that the

fundamental role that carers were undertaking in society started to be understood and acknowledged. Much of carer-related policy and legislation has taken place within the context of health and social care reform over the last 30 years

Table 1 gives an overview of key legislation and policy for carers since 1995

In the 1990s recognition of the caring role and the needs of carers became part of public policy. Thus in 1995 the Carers (Recognition and Services) Act became the first piece of legislation to give those carers providing 'regular and substantial care' rights to an assessment of their individual needs. Data on carers has been collected since the 1980s and in the 2001 and 2011 census a question on carers was included. Since the 1995 Act there have been a series of successive policies, legislation and strategies that have been predicated on carers' recognition and rights; services for care recipients and carers; reconciliation of work and care and financial support. Such policy and strategy within the health and social care sectors has also focussed on enabling carers to have a life outside of their caring role. The rights to a needs' assessment have therefore been enshrined in law since 1995. However subsequent Acts have strengthened and extended the rights of carers.

More recently, and in recognition that social care law was complex and fragmented the coalition Government introduced the Care Bill to parliament in 2013 and the Care Act was passed in 2014. This was established to unify adult social care statute. This legislation is significant and gives carers parity with those in their care. The Act strengthens carers' rights for an assessment, places a duty on Local Authority's (LA) to fund carer support for their 'eligible' needs and legally entitles carers to information and advice (Department of Health, 2014). The Care Act is based on several universal provisions and duties that apply equally to carers and care recipients. The principles of promoting wellbeing and preventing and mitigating needs are central tenets.

Table 1: Key Developments in Carer Policy and Strategy over a 30 Year Period

Legislation/Policy/Strategy	Key Provision/Areas
Carers (Recognition and Services) Act, (1995)	The right of carers providing 'regular and substantial care' to an assessment of their own needs.
Caring about Carers, First National Strategy (HM Government, 1999)	Premise was to enhance the quality of life of carers through greater support and information. A carers grant administered via LA was possible for carers to take breaks
Carers and Disabled Children's Act, (2000)	Increased LA powers in support of carers. This included; direct services to carers; independent (to the care recipient) carer assessments; the use of Direct Payments to carers; greater flexibility for LA to offer carer breaks.
Carers Equal Opportunity Act, (2004)	Carers to be informed of their rights to an assessment becomes a duty of the LA
Work and Families Act (2006)	This enables the right to request flexible working for those employees caring for an adult
Our Health Our Care Our Say (DH, 2006) announced a new deal for carers within the white paper	Committed to update a Prime Minister's strategy for carers. A national information service and training were part of this. LAs were also to receive funding for emergency at home, respite care to support carers in crisis. Emphasises personalisation within the white paper
Pensions Act (2008)	Enhances pension rights for carers
Carers at the Heart of the 21 st Century (HM Government, (2008)	Carers to be universally recognised, valued and seen as expert care providers, key to family structures and the wider community. Support to balance caring and a life outside the role; carer finances and health and wellbeing are a focus. Children and Young People will be protected from inappropriate caring and receive the support they need.
Recognised, Valued, supported (Next steps for the Carers Strategy) (Department of Health, 2010a)	Developed by the coalition Government, 4 areas are addressed: Identifying and recognising carers; realising and releasing carer potential; a life outside caring and carer health.
Equality Act (2010)	Protects carers from discrimination by association

Table 1 (continued): Key Developments in Carer Policy and Strategy over a 30 Year Period

Legislation/Policy/Strategy	Key Provision/Areas
Care Act 2014	A significant piece of legislation. Carers given new rights for an assessment and 'parity of esteem' with the care recipient. LA's have a duty to provide information and fund support for carers' eligible needs
RCGP and NHS England (NHS England, 2014a) Commissioning for Carers: Principles and Resources to Support Effective Commissioning for Adult and Young Carers /NHS England's Commitment to Carers (NHS England, 2014b)	Commitment identifies priorities, including: Raising the profile of carers; education, training and information; service development; ; person-centred, well-coordinated care;; primary care; commissioning support;; partnership links; and NHS England as an employer. Commissioning for Carers Principles focus on key actions to achieve the best outcomes
The NHS Constitution (Department of Health and Social Care, 2015)	Commits to work in partnership with patients and carers and to co-ordinate, and tailor care around the needs and preferences of patients, families, and their carers.
NHS England's Carers Toolkit (NHS England, 2016)	Covers new duties on NHS organisations from the Care Act 2014 and the Children and Families Act 2014. Includes Memorandum of Understanding for integrated working between Adult social care services, NHS commissioners and providers and Third Sector Organisations, to identify, assess and support carers and their families across health and social care.
Carers' Action Plan 2018-2020 (Across Government) (Department of Health and Social Care, 2018a)	Structured on the following themes: services and systems that work for carers, employment and financial wellbeing.
UK Government Mandate to NHS England 2018-2019 (Department of Health and Social Care, 2018b)	Carers to be identified and given access to information and advice about the support available
NHS Long Term Plan (NHS England, 2019a)	Commitment to improve support for carers and develop more personalised care for patients and carers
Universalised Personalised Care 2019 (NHS England, 2019b)	Whole-population approaches to supporting people of all ages and their carers to manage their physical and mental health and wellbeing, build community resilience, and make informed decisions and choices when their health changes.

Adapted from Henwood et al., (2017) Key LA= Local Authority; CAYP= Children and Young People.

1.7 The Carers' Position in Society: The Micro, Meso and Macro-Level Perspectives

In this section the broader ecological position (Cantor, 1991; Connidis & Barnett, 2019) in terms of the carers' role within society will be examined. Further consideration will be given to how the wider social, political, cultural and economic structures impact and shape their caring role. Care is an activity that has distinct relational properties. It is located at the 'intersection of state, market and family (and voluntary sector) relations' (Daly & Lewis, 2000, p. 296). The carer's position therefore becomes pivotal and their role across the wider networks connects them to the micro, meso and macro levels of society (Daly & Lewis, 2000; Pickard, 2010; Solimeo, 2009; Twigg & Atkin, 1994). Across their life course, carers' individual circumstances are influenced by their personal identity (including age, gender, sexuality, race, socio-economic status, and ability) the era they were born and the historical context of their lives. Their lives are 'linked' and uniquely interconnected with others, and in these relationships, further reciprocal influences occur (Connidis & Barnett, 2019; Finch & Mason, 1993; Solimeo, 2009). Personal cultural beliefs and expected normative behaviours in society also affect how these ties are negotiated maintained and evaluated (Connidis & Barnett, 2019; Finch, 1989; Finch & Mason, 1993; Solimeo, 2009). Carers' personal connections to family, friends, and the local community act at a micro level. Meso-level connections to other social domains and institutions such as work, or health and social care provision have a further impact on their role and the negotiations associated with those (Egdell, 2012a) Finally connections to more over-arching political institutions and the discourses that occur in society offer a macro-perspective of influence on the carer (Pickard, 2010). The carer's biography and position in society through these connections and the reciprocal influences they exert influence the carer's experiences and outcomes over their lifetime.

Although informal care is often located within the family and is more often provided by spouses and female kin (Phillipson, 2001; Pickard, 2008; Ungerson, 1983), it is also situated in wider societal and cultural contexts (Sims-Gould & Martin-Matthews, 2008; Solimeo, 2009; Ungerson, 2000). Demographic changes are altering the structural composition of the family, as are social trends. This includes serial and same sex marriage, cohabitation, delayed childbearing, and the increased numbers of women in

the workforce (Silverstein & Giarrusso, 2010). Thus, the traditional model of the family is changing with more pluralistic family structures evident in society (Roberto & Blieszner, 2015). Family responsibilities are increasingly recognised as unique and personal with variations that reflect commitments and relations as they develop through the biography and shared history of close relationships (Connidis & Barnett, 2019; Phillipson, 2001). As family structures have changed and mobility has led to the geographical dispersion of families, the increasing significance of relationships with friends and neighbours has also become apparent (Pahl & Spencer, 2004). These relationships have also been recognised as sources of care for older people (Ward et al., 2012; Wenger, 1993).

Almost 30 years ago Twigg and Atkin (1994, p. 11), in relation to service provision, commented on the 'ambiguous' position of carers as the pace of the community reforms increased and expectations of the carers role became integral to the pursuit of care in the community. More recently Egdell et al. (2010, p. 103) have argued that 'as carers and care recipients occupy an intersection between the domestic and healthcare fields, they have an uncertain and evolving position in the web of social relations'. Therefore, within the wider meso-context of care-giving many other individuals may form part of the overall 'care' network. These may include those who are paid to provide care and those who volunteer. Thus, carers such as professionals and support workers within health, social care and other community and voluntary organisations may form part of the carers' networks of support

From the previous discussions it is evident that the changing demographics with a move to community care, where resources are scarce, has led to an increasing reliance on carers in the delivery of care and support to the most vulnerable in society. Therefore, one might expect that this increasing acknowledgement of the role and the focus on carers through wider Government policy, legislation and specific policy initiatives and practice in the health and social care sectors has purported to empower carers (Larkin & Milne, 2014). However, for carers of older people there appears to be a paradox and heterogeneity of recent discourse in terms of their role (Pickard, 2010). Whereas a more traditional discourse continues to be reflected in health and social policy with an expectation of care from the family, there is a competing liberal discourse relating to choice and autonomy for individuals within society (Pickard,

2010). Carers therefore appear to occupy a liminal position as there continues to be a move away from the provision of welfare services for the family, and more private care alternatives for those they care for, with reductions in the availability and range of resources (Humphries, 2011). Criticism has been directed at the policy makers arguing that their response to the situations that carers find themselves are purely rhetorical, since in reality there has been a mismatch between the duty to assess and the lack of choice and availability of services to meet carers' and care recipients' identified needs (Carers UK, 2019; NAO, 2018a; Pickard et al., 2016). Although LAs have sought to support the most vulnerable they have encouraged self-sufficiency with families and communities expected to draw on their resources, to reduce the dependency and support from the state. Thus, an individual's financial circumstances i.e., what they can afford and their postcode, rather than 'need' can determine the care they receive (Humphries et al., 2016) Carers, therefore continue to experience difficulties in both the interpretation and the implementation of legislation and policies (Carers UK, 2019; Glendinning, 2012).

1.8 Studying Carers' Social Networks and the Concept of Social Capital

The nature of the carer's social network and the multiple contributions that may assist or support the carer in their role can be viewed conceptually through a systems model (Cantor, 1979;. Cantor, 1991) or a convoy model that recognises the giving of care as being situated within a network of individuals (Antonucci, 1985; Antonucci, Birditt, & Akiyama, 2009; Kahn & Antonucci, 1980). Social networks, with their associated ties and ensuing relationships and the care provided in these structures are central to both. Within the various social networks of carers with their ensuing interactions that link carers to society, are shared understandings and norms of behaviour that shape these interactions and co-operation between individuals and society (Halpern, 2005; Portes, 1998; Putnam, 2000, 2004). The concept of social capital proposes that the nature and extent of these social relationships form assets that can be beneficial (Bourdieu, 1986; Coleman, 1988; Granovetter, 1973, 1983). Such assets can therefore benefit individual carers, their communities and society (Field, 2008). Although this work will

focus on carers' social networks and social capital it will acknowledge the carer's individual demographics and circumstances (be it cultural, financial, or emotional) since these too can impact on their disposition and ability to provide care (Broese van Groenou & De Boer, 2016; Roberto & Blieszner, 2015).

1.9 Summary

This introduction has considered the social, political, economic, and cultural factors that are shaping the provision of care to the elderly and those with PD in the UK in the 21st Century. It is evident that the changing social and demographic contexts of the UK are leading to micro-and meso-level changes that impact on family and community structures that further influence the care of older people. Successive Governments have acknowledged that carers will be vital in supporting the NHS and social care to provide care to an increasing, ageing population. Government policy and accessibility to care and support outside informal (unpaid) care is therefore determining not only who provides care, but also how it is provided and where that care takes place. The role of health and social care support and provision has changed particularly in the last 30 years, and this too has altered the relationship of carers and care-recipients with those previously viewed as the formal providers of care. This consumer-provider model of care is driven by an ethos of personalisation with an emphasis on choice and control. However, many carers have little choice in becoming a carer and find that services and support from the state and wider society lacking and inadequate.

Although caring often takes place within family structures, greater pluralistic models of family life are emerging. Carers are situated in a web of social relations. Carers in their role find themselves positioned at boundaries between their domestic lives and the providers of health social care; between family and friends and between their own sense and understanding of their role and the social and cultural expectations and demands of society. Supporting and managing the care of a long-term condition requires personal resources. The carer's personal biography and life-course influence and determine these resources. Although there has been an increasing empirical focus on the nature and types of social relationships and networks in old age, more empirical work is required in the UK to encompass those informal carers and care-

recipients dealing with PD. This will further elucidate the carers' networks, uncovering the available social capital and the resources within these networks that may aid in their caring role.

1.10 Research Aims

This study therefore aims to offer a deeper understanding of the position carers of those with PD in their individual social relationships and network structures using social network theory and the concept of social capital. Utilising a case study design allows the collection of social network data, complemented by qualitative diary and interview data. Twenty carers were recruited with the aid of Parkinson's UK³. The participants lived in London and the home-counties.

The study aims to determine the following:

- The structure of carers networks-in terms of dyadic relationships, shape and distribution of 'ties'
- The carers use of those networks in their caring role
- The inherent resources within the network, including flows of information and leverage and if the resource is used for personal (or collective) means.
- How access to these resources is achieved (or if access is denied)
- If there are negative features within these networks that can be detrimental to the carers' role.

³ Parkinson's UK is a registered UK charity that is at the forefront of research into PD. It supports those with PD along with their families and carers. It has an extensive network of local groups that facilitate this support. Information and advice are also available via online forums and telephone helplines. Local excellence networks also support a range of health and social care professionals who care for those with PD.

- The presence of health and social care services alongside other community provision within these networks and their role and function to the carer

1.10.1 Research Questions

This study will explore these issues by focussing on the following research questions.

- What are the forms, functions, and associations of carers' social networks?
- How do carers access and utilise the resources contained within these networks?
- How do their social networks impact on their caring role?
- What is the role of the health and social care sectors and the local community in shaping or developing carers' social networks?

1.10.2 The Wider Contribution of this Study

This study can support and determine the formulation of policy and strategy in delivery of support for carers. It can also assist in the planning of services and interventions to ensure that carers and those they care for are most appropriately supported, and the associated resources managed most effectively.

1.11 The Structure of the Thesis

Chapter 2: The Literature Review

This literature review will be presented in two parts. Initially a broad critique of the literature regarding the concept of care and caring from a socio-political and economic context is presented. The nature of the social networks of older people and the concept of social capital will be examined. The carers and care-recipient's position within the informal and formal care networks will be assessed in relation to changing socio-demographic structures and health and social care policy. In part two a systematised

review of the literature in relation to the social/care networks and social capital of carers and care-recipients is presented.

Chapter 3 Part1: Methodology

This will provide a comprehensive justification and discussion on the chosen methodological approaches that relate to the case study design and the use of social network data collection tools. Ethical considerations and the process of recruitment are examined. The maintenance of quality and rigour and the associated challenges encountered in carrying out the research will also be discussed

Chapter 3 Part 2: Data Analysis

This section will describe how the interview and diary data from 20 carers were analysed using Ritchie and Spencer's (1994) framework technique. The use of social network analysis to elucidate and visualise the social network data will also be presented.

Chapter 4: Introducing the Carers

An introduction to each carer will be provided with an overview of the key biographical features of the participants.

Chapter 5: Results

The Carer's 'Personal Community': Bonding Together and Bridging Beyond

This chapter will examine the form and function of the carers' 'Personal Communities' and those intersecting factors that impact and shape the composition of the networks.

Chapter 6: Results

Third Sector Organisations (TSOs): Bridging and Connecting: *A whole new world has opened up to us.*

This chapter will consider how TSOs shape and influence the carers' networks and gives a detailed view of the carer and care-recipients' entry into these organisations.

Through bridging social capital, the benefits that can ensue through the connections made are elucidated.

Chapter 7: Results

Health and Social Care Provision: Establishing and Maintaining Links

The final empirical chapter will consider how the carers' interfaced with health and social care provision. This describes a varied and disparate picture of support that is dependent on the carers' personal resources and local access to provision.

Chapter 8: Discussion

This chapter will discuss the study's contribution to knowledge and how the findings may inform health and social care practice and future policy agendas. The benefits and limitations of the study will also be considered

Chapter 9: Conclusion

This chapter will summarise the key findings

Chapter 2: The Literature Review

2.0 Part 1: Parkinson's Disease and The Networks of Informal and Formal Care

2.1 Introduction

Parkinson's Disease (PD) is a complex, heterogenous condition that can have a protracted illness trajectory. Providing care for somebody with PD can be a prolonged and difficult journey which will alter and shape the lives of the care-recipient and their carer (Solimeo, 2009). Caregiving may occur at different stages through the life course and the needs and experiences of the carer as they undertake their role will vary according to the life stage that they are at. Their individual disposition, personal attributes, and immediate social situation alongside the wider societal, political, economic, and cultural contexts, will all influence the needs and experience of the carer. Over the last 30 years, Government policy with the focus on care in the community has promoted an expectation that informal care provided by carers and those that form the social network of the care-recipient will be a significant source of long term, principally home-based care. Such care has been viewed as responsive with shared biographies, established relationships and normative obligations and expectations based on previous reciprocity and accepted mutuality (Connidis & Barnett, 2019; Finch, 1989; Finch & Mason, 1993; Phillipson, 2001).

Care takes place within dyadic relationships and may involve individuals including close kin (parents, children, spouses, and siblings) to more distant relatives alongside friends and neighbours. It is argued that 'care-giving' networks evolve from social and support networks (Keating, et al., 2003). As the care network evolves it becomes more specific and the defined nature of the activities associated with care lead to a smaller network size. Societal and on-going family demographic changes are now also impacting on the capacity and availability of the informal network to provide care. These changes have included women's increased participation in the workplace with

competing care-giving demands, falling birth rates, increasing divorce rates and greater geographical mobility (Pickard, 2015; Roberto & Blieszner, 2015; Silverstein & Giarrusso, 2010). Utilising predictive models, Pickard, (2015, p.96) has forecast that over the next two decades there will be a significant 'care gap' in England. The increasing demand on adult children to care for older people with disabilities will exceed supply and there will be a shortfall of 160,000 carers (Pickard, 2015). Alongside such predictions others have also highlighted the fragile and precarious position of informal care (Egdell et al., 2010; Rutherford et al., 2014; Wenger, 1997).

Austerity measures during the last decade have also led to decreasing formal care provision within the community and institutionally, which is also placing greater demands for care on family and friends with health and social care viewed as supplementary to the care provided by informal means (Carers UK, 2015; Humphries, 2011; Humphries et al., 2016; National Audit Office (NAO), 2016). Evidence indicates the care needs of those at home are not being met (Vlachantoni, 2019; Vlachantoni et al., 2011) and tensions and constraints arise as families are expected to care for those who are dependent, but potentially lack the capacity or propensity to do so (Broese van Groenou & De Boer, 2016; Roberto & Blieszner, 2015) Research activity has focussed on the carer-care-recipient dyad (Henwood et al., 2017). However, greater research is needed to examine the structures and capacity of the social networks of older people and their carers to provide care (Carpentier & Ducharme, 2003; Egdell, 2012a; Egdell, 2012b; Keating et al., 2003; Rutherford et al., 2014). This offers a distinct approach to clearly delineate those who are providing care and the factors that aid or impact on that provision. It also facilitates a closer examination of the relationships within those networks (Carpentier & Grenier, 2012; Moen & DePasquale, 2017)

This literature review has been divided into two main parts. In part one a broad critique of the literature regarding PD and the concept of care and caring from a socio-political and economic context is presented. The social and relational dimensions of care are considered in terms of examining the importance of the social networks of older people and the resources and support that these might offer. To further examine the inherent resources within these networks the concept of social capital will be critiqued. The evolving position of the carer and care-recipient within the informal and formal care

networks will be discussed in relation to changing socio-demographic structures and health and social care policy. In part two a detailed systematised review of the literature pertaining to the social/care networks and inherent social capital of carers and care-recipients is undertaken. This considers the characteristics of the networks, their function, resources, and the associated social and relational processes that occur. The position and role of community and formal care provision will also be examined with analysis of the interface between the informal and formal care sectors.

2.2 The Broad Literature Review

A range of literature was searched to examine care in a wider perspective that included evidence and policy alongside the substantive literature on Parkinson's Disease (PD) and the historical, conceptual, and philosophical understanding of care and caring. Databases used included:

- BNI
- CINAHL Plus
- MEDLINE
- SCOPUS
- TRIP
- Web of Science

Lateral search techniques were also used including the grey literature and utilising references from pertinent articles.

2.3 The Context and Challenges of Parkinson's Disease

The incidence and prevalence of PD is increasing (Okunoye et al., 2019) in line with the demographic shift to an ageing population. In 2018 for people aged over 20 in the UK, the figures suggest that there were 145,519 people living with PD. The prevalence in men is 1.5 times that in women in the 50-89 years range (Parkinson's UK, 2017). Overall, prevalence is expected to increase by 18% between 2018 and 2025 with 168,000 people affected. Thus, by 2025 the estimated yearly incidence will rise to over

21,000 and with a doubling of both prevalence and incidence by 2065. The economic cost of the disease is significant, with both the direct costs of formal health and social care, alongside the indirect costs associated with loss of productivity when employment is affected, and the economic and emotional cost to individuals and their informal carers (Findley, 2007). The disease particularly manifests as a progressive loss of motor function. Early symptoms may include tremor, stiffness and changes in posture and facial expression. The progressive nature of the disease leads to increasing difficulties with mobility and outwardly visible signs. The overt motor symptoms can also be accompanied with other debilitating cognitive effects including dementia, anxiety and depression, hallucinations, impulsive disorders and psychosis (Kouli et al., 2018). The overall effects and impact overtime lead to increasing morbidity and levels of dependency (Kalia and Lange, 2015). Classic signs and symptoms include freezing (a momentary inability to move), impairments in executive functioning, gait changes and ataxia noted by reduced speed and decreased amplitude of leg movement (characteristically seen as shuffling). Other distressing effects can include further motor dysfunction as seen in dyskinesia (uncontrollable spasm-like movements) and non-motor effects such as drooling and constipation (Kouli et al., 2018). Pharmacokinetic and pharmacodynamics interactions of the medication can lead to on-off syndrome (as function is lost between medication doses), hallucinations and compulsive behaviours (Kalia & Lang, 2015; Lees et al., 2009). The changes to dopamine production in the brain can lead to neuropsychiatric symptoms that may be compounded by the medication. As PD progresses the intractable symptomology often requires increasing the type and range of medication. Thus, higher dosages of medication and polypharmacy often become the norm of treatment. For both the individual and the carer this medicine regimen can come to dominate their lives (Gibson, 2016; Solimeo, 2009).

2.3.1 Why Study the Networks of Informal Carers of those with Parkinson's Disease?

The neurological origins of the disease with its concomitant symptomatology as described in section 2.3 has led to major avenues of research into PD. These have predominantly followed a biomedical model, focussing on the neurological pathophysiology, physical, and cognitive manifestations of the disease, alongside the

development of novel treatments particularly centred on pharmacological approaches. However, there remain significant gaps in understanding how living with a long-term condition such as PD impacts on those with the disease and their carers (Solimeo 2009; Stanley-Hermanns & Engbretson 2010; Gibson & Kierans, 2017). As described in section 2.3 and in more detail in sections 2.4- 2.6, PD is a complex disease which can have a protracted trajectory (Greenland and Barker, 2018) with a mean duration from diagnosis to death of 15 years (Lees et al., 2009). The physical changes, (as described in section 2.3), can lead to significant disability with a need for increasing support with the activities of daily living. The cognitive manifestations of PD can also be variable and may include dementia and psychosis. Thus, over time the physical, cognitive, psychological, and social demands of the disease have an increasing impact on the individual and their carer. These demands are particularly unique to this disease, they are unpredictable and context dependent and, as the disease progresses, those activities that are innate, routine and taken for granted become increasingly disrupted (Haahr et al., 2011; Haaxma et al., 2007; Bramley and Eatough, 2004; Solimeo, 2009, Gibson and Kierans, 2017; Nijhof 1995) These disruptions alter the concept of self and impact on not only the individual with PD but their carers also (Charmaz, 1991; Gibson and Kierans, 2017; Solimeo, 2009; Lindgren, 1996; Aarsland et al., 1999; Williamson et al., 2008; Lyons et al., 2009; Schrag et al., 2006). Consequently, patients and their carers may spend many years dealing with, and managing, the disease.

As will be discussed in more detail in section 2.5, the limited research on carers of those with PD does illuminate carer distress and burden (Gibson and Kierans, 2017; Solimeo, 2009; Lindgren, 1996; Aarsland et al., 1999; Williamson et al., 2008; Lyons et al., 2009; Schrag et al., 2006). Yet despite experiencing increasing debility due to motor and non-motor symptoms, only 25% of those with the disease access formal domestic support services, suggesting that much of the care required is being delivered by informal carers (Hand et al., 2018). This would also suggest that carers (and care-recipients) may be drawing on their own networks of support to deliver and maintain care within the home setting. Although there is an increasing recognition of the value of social support and social networks, much of the work, in terms of caregivers, has focussed on those caring for those with Alzheimer's Disease or dementia. Despite PD being the second most common neurodegenerative disease,

and the numbers of people affected increasing due to demographic changes, there has been no detailed study of the range of networks (informal and formal) that may support the care needs for such a chronic, progressive illness.

The third sector, including voluntary and community organisations (VCOs), play an important role in supporting patients and carers who are managing a range of conditions (Jeffries et al. 2015; Morris et al., 2015; Vassilev et al., 2014). There is only one study that has highlighted that peer-led support groups may offer a valuable means of support for carers of those with PD (Abendroth et al., 2014). The findings indicated that this sector has a valuable contribution in assisting carers in their role and would suggest that this should be an avenue of exploration in the UK. Parkinson's UK was established as a charity to research PD and to support those with the disease and their carers through a network of local groups. This study will access carers through Parkinson's UK, and this may help to uncover how this organisation (and other VCOs) offer support and assistance.

Understanding the informal care of those with PD and their carers (be it family, friends, or community organisations) and how this support is utilised, can facilitate an understanding of the social dimensions of care provision. Examining more formal structures of care that surround the carer and care-recipient from their perspective also gives a unique view that can further illuminate the effectiveness or deficits in service provision. It is in this current gap in our knowledge of PD that this study will contribute.

2.4 Parkinson's Disease: The Lived Experience

The heterogeneous and uncertain trajectory of PD affects individuals, their carers, and others around them in unique ways. The dominance of the biomedical model of PD has led to a greater knowledge of the cellular changes within the brain and development of novel and varied treatments has been possible. Many of the symptoms remain a significant part of everyday life for those with the disease and those caring for them. A body of evidence is developing that has looked beyond the symptomatology and aims to examine not only the somatic phenomena of PD but an understanding of the sociological, psychological, and cultural impact that the disease can have. The individual's particular circumstances and situation with a perceived lack

of control, stigmatisation, increased social isolation, and a sense of loss and grief alongside the increasing disabling effects of the illness can also impact on the individual's well-being (Caap-Ahlgren et al., 2002; Gibson & Kierans, 2017; Hermanns, 2013; Pinder, 1992; Solimeo, 2008; 2009; Stanley-Hermanns & Engebretson, 2014; Williams & Keady, 2008)

Diagnosis for PD patients can be a time of maximum 'experiential incoherence' (Pinder, 1992, p. 1) as little has prepared them for the diagnosis and its impact is biographically disruptive (Bury, 1982; Williams & Keady, 2008) with a sense of no return. The outward signs and manifestations of the disease produce visible 'stigmatising signs' (Solimeo, 2009, p.18). Classic symptoms of PD i.e., tremor, drooling, stumbling, shuffling gait can be mistaken for inebriation. Sufferers are often embarrassed by their symptoms and have highlighted a sense of shame (Gibson & Kierans, 2017; Caap-Ahlgren *et al* 2002). Nijhof (1995), using a social constructivist perspective, argued that the symptoms are out-with acceptable forms of public behaviour. Shame arises from 'rule-breaking' (Nijhof, 1995, p.193), those aspects that regulate everyday life. Both those with the disease and their carers attributed this shame to the 'outside world' (Nijhof, 1995: p.194) since public display and visibility provoked reactions in others and added to the shame associated with the disease.

Solimeo (2008; 2009) undertook a detailed ethnographic study in the United States using participant observation at PD support group meetings, narrative interviews, and a questionnaire. She examined, with sufferers and their carers, how those with PD have their experiences shaped by wider social relations and inequalities. By addressing the cultural world of PD sufferers, Solimeo found that age, and gender, alongside social location, were uniquely integral to an individual's PD subjective experience. The PD experience is influenced by gender, with men and women having very different experiences. For men they were concerned with the physical body in relation to the public view. Thus, a theme that recurs in the literature for male sufferers of PD is those aspects of physical performance with the outward physical signs of the disease such as poor posture, debilitation, and limited physical activity all impacting on their masculinity (Solimeo, 2008; Gibson & Kierans, 2017). The concerns of women however, focused on stereotypically female areas of competence such as domestic activities and social relationships. For both males and females, role continuity was

important, and therefore drew on their abilities that are typically associated with gender to understand or make sense of their PD (Solimeo, 2009).

Solimeo (2009) also uncovered that those social beliefs and expectations associated with the ageing process and ultimately old age, also shaped an individual's understanding and experience of the disease. The possibility of decline with ageing becomes an 'inevitable one' (Solimeo, 2009, p.18). Thus, the disease was mediated by age and the process of ageing. There is an inter-play between the two as ageing obscures the disease and the disease process accelerates the ageing process. Ageing, alongside social and cultural factors also intersected with their changing sense of embodiment through their life course.

2.5 Parkinson's Disease: The Carer's Perspective

The progression of PD is such that it often requires the support of an informal carer. The role of the PD carer is important in supporting disease management and the activities of daily living (Vatter et al., 2018). The role for carers of those with PD can be challenging with support centred on the emotional dimensions of care, assistance with personal care including washing, dressing, and feeding and general household tasks (Hand et al., 2019). There is a growing body of evidence that has examined the carers' experience of looking after somebody with PD. The heterogeneity of the disease and its progression does give each carer and care-recipient a unique experience within their own personal, social, and cultural context (Williamson et al., 2008; Solimeo, 2009). Therefore, the experiences of carers can vary widely (Martinez-Martin et al., 2008; Schrag et al., 2006; Solimeo, 2009). Research has focussed on the physical, psychological, emotional, social, and financial impacts of caring in the context of the 'burden of care' (Henwood et al., 2017; Zarit et al., 1986) and it is now argued that caring can be viewed as a social determinant of health (Public Health England (PHE), 2021). For carers of those with PD, as is evident in the wider carer literature, they too will experience carer strain due to many conflicting emotions and personal difficulties as they deal with the diagnosis and the day-to-day difficulties of coping with the disease (McLaughlin et al., 2011; Oguh et al., 2013). Furthermore, lifestyle changes that may affect work (and therefore finances), or restrict social

activities and engagement, can also become a reality (Abendroth et al., 2012; Hounsgaard et al., 2011; Williamson et al., 2008). The various manifestations of PD in the care-recipient can all impact on the carers' mental and physical health (McLaughlin et al., 2011). Thus, prolonged disease duration and increasing physical needs (Martínez-Martín et al., 2007; Schrag et al., 2006) along with cognitive decline and neuro-psychiatric symptoms (Schrag et al., 2006; Williamson et al., 2008) are especially linked to carer distress and burden. Demographically, female carers have greater role strain over a ten-year period, although high mutuality and optimism with low pessimism early in the disease has protective effects (Lyons et al., 2009). A decline in the carers' health with 'burnout' can affect the carers' quality of life, with an increased burden and strain eventually leading to long term institutional care of the care-recipient (Abendroth et al., 2012).

Solimeo's (2009) ethnographic work also highlighted how the carers in her study of PD managed and adapted to the condition. In this work, the interdependency of the carer/care-recipient dyad (all were spouses) was evident. The disease impacted on all aspects of their relationship and the carer's role evolved as the disease progressed. The carers experienced physical and emotional strain and reported on a wide range of activities that they performed as part of their caring role. These included medication management, co-ordination of appointments, and a variety of household tasks and financial duties. In examining the relational dimensions of caring, Solimeo, noted the carers embarrassment of the outward signs of the disease as described by others in relation to sufferers with PD (Caap-Ahlgren et al., 2002; Nijhof, 1995) and this was often linked to bodily fluids and the work of physically caring for their spouse's body. In Solimeo's work, social withdrawal of the care-recipient impacted on the carer with diminishing social interactions, engagements, and reduced contact with friends and because of friends withdrawing their contact. The time taken to meet the demands of caring and the complexity and timing of medication also made social activities more difficult. The positive aspects of caring as described in the wider literature (Pinquart & Sörensen, 2003) are also evident for those caring for somebody with PD. Thus, the care-recipient's gratitude, time spent together, and the purpose that the carer role provides are viewed as gains (Solimeo, 2009). Mutuality and togetherness in dealing with a chronic condition (as noted by Aasbø et al., 2016) also appears to have positive

effects as couples maintain their interdependency and renegotiate their roles (Lyons et al., 2009).

2.6 Parkinson's Disease: Formal Care Provision

Clinically there is an understanding that the complexity of PD requires careful and effective management. The National Institute for Health and Care Excellence (NICE) (2017) has updated guidance to address the demands of caring for and managing PD patients. Within the UK there are a variety of models for care provision. Most sufferers with PD experience a multi-disciplinary service. Consultant neurologists or geriatricians with an interest in PD normally lead the service and there may be access to a PD nurse specialist (Read et al., 2019). Carers have reported that health professionals do not integrate them within the care trajectory, with a lack of coordinated care plans, symptoms being poorly managed and support for relatives and carers being missed (McLaughlin et al., 2011). From the Parkinson's (2019) audit of the quality of care as reported by service users and carers, it was found that improvements were needed in the following areas: wider access to specialised multidisciplinary services; standardised practices; improved communication and information sharing; better medicines management and more support for the workforce. Referrals to a wide range of Allied Health Professionals are recognised as essential to manage both motor and non-motor symptoms. Integral to care is careful medication management through timely administration when an in-patient and at home. This is complicated by the potential side-effects of drugs causing hallucinations and delusions. In recognition of the difficulties associated with the services for those with a progressive neurological disorder, NHS England (2019c) has released a toolkit to aid commissioners to address the challenges for care.

As the disease progresses the complexity of the care needs also increase with the potential for greater support required from the health and social care providers. However, a recent survey of all PD service users who were still living at home and under the care of a Trust facility in the North East of the UK, found that only 25% accessed formal domestic care and the same percentage formal personal care (Hand, et al., 2018). Eighty per cent of those surveyed identified an informal carer who

supported them with either/or both domestic and personal care. Thus, the use of formal care services was uncommon with informal carers performing much of the care. These findings were surprising since the care-recipients all had significant motor and non- motor symptoms that suggested that much of the care need was not being met by formal services but by informal carers. This also aligns with Carers UK (2016b) findings. It is recognised that as the care burden becomes unsustainable for carers of those with PD, there is a risk that for institutionalisation will be the only option (Abendroth et al., 2012).

2.7 The Concept of Care

Defining and conceptualising care is difficult as the task or instrumental activity in 'caring for' needs to be reconciled with the emotional aspects of 'caring about.' (Ungerson, 1983, p. 31). Thus, caring can be both a practical activity and an affective state. Caring and caregiving are situated in complex social relationships which are contextually and historically located (Finch and Mason, 1993; Fine and Glendinning, 2005; Barnes, 2012; Connidis and Barnett, 2019). Thus, in examining care it is important to consider and distinguish those features and meanings of care within the social, economic, and political contexts of society, alongside care provided by family and friends and that within the formal sector.

The act of caring is uniquely bound to the relationships that are part of the processes of care. For Bytheway and Johnson (1998, pp. 252-253) this is considered as follows:

[care] relationships are normally set in the context of 'ordinary' networks of personal relationships, networks which normally include a complexity and multiplicity of care needs. ... [Later].. that care relationships are often mutual, that most people who are involved in both receiving and providing care, albeit perhaps in very different ways.

The temporal and contextual dimensions of care can lead to shifting dependencies and developing interdependencies as relationships evolve (Fine and Glendinning, 2005; Finch and Mason, 1993). Kittay (1999, p. 67) also uses the term 'nested dependencies' to illustrate how exchanges (in the form of care) between individuals

may be direct and immediate reciprocation or may be delayed or even transferred to others in the network.

There has been a growing interest in the concept of care and the role of carers since the 1980s, as academics began to explore the concept particularly from a feminist perspective. This was set against social and political changes as in the second half of the 20th Century women increasingly began to take up paid employment. The private sphere of home and work were no longer clearly separated but began to blur since what had been an institutional and gendered separation (the man at work and the woman in the home) began to change as women increasingly became part of the work force and spent less time in the home. Finch and Grove's (1983) collection of papers explored the gendered nature of care in the domestic setting and within the context of government policies that were beginning to emphasise care in the community. Insights were gained from this about the nature of caring and how women juggled their domestic lives with the increasing demands of employment. Thus, the focus was on women and their roles within the family and society (Graham, 1983; Ungerson, 1983) and the work that they performed in caring (Walker, 1983). The nature of power relations in society through the structures of marriage and the economics of work and the division of labour were also considered (Rimmer, 1983). Over time this scholarship was extended to address paid care (Graham, 1991) and the increasing role of policy and the state (Ungerson, 1990) alongside the interface of informal care with formal care provision (Twigg, 1989; Twigg and Aiken, 1994; Twigg, 1999). This work offered the early foundations for the evolving empirical literature in this area.

More recently caring is being characterised by its interdependent nature with mutuality and reciprocity core in the giving and receiving of care (Barnes, 2012) with a blurring of the boundaries between the carer and care-recipient (Aasbø et al., 2016; Larkin & Milne, 2014). Thus, the relational aspects of the carer and care-recipient dyad have been key strands in the research. However, this dyad is often 'nested' (Kittay, 1999, p. 132) within wider social relations or convoys of care (Kahn & Antonucci, 1980; Antonucci, 1985; Antonucci et al., 2009; Cantor, 1991).

The concept of care has also been developed from an ethical and moral position. In this approach, there is a view of care as encompassing society and care as a power for good. Thus, this emphasises the norms and values which guide and underpin care and it is viewed as a model of social relations (Barnes, 2012). Tronto, (1993), views care as both a moral and political issue and therefore these cannot be separated. The values of care can act to underpin human action across a range of social fields (Sevenhuijsen, 2000). Tronto, (1993), has proposed four principles that are overarching in the provision of care; attentiveness, responsibility, competence and responsiveness. Trust (Sevenhuijsen, 1998) and respect (Engster, 2007) have also been added to these principles. These can help to shape and guide the process of care through the recognition of the need in others and an acceptance of responsibility to meet those needs. Therefore, where there is need, care should be provided, with an assessment of the outcomes of that care (Barnes, 2012). In relationships of care, trust facilitates dialogue and negotiation between care givers and those receiving care. Respect ensures the recognition of others' capabilities and understanding. Thus, this ethic of care can be used to assess how care is socially provided and how it is valued (Sevenhuijsen, 1998; Barnes, 2012).

This approach in re-iterating the relational dimensions of care, allows a consideration of those social institutions where care takes place and within the wider socio-political and economic context (Connidis and Barnett, 2019). Care is therefore extended from that provided within the micro domains of family life and the informal structures of care but reaches out into society. Thus, care becomes a way of being in society and a means of making connections (Daly 2002).

In relation to this study and the care of those with PD, the carers' personal connections to their informal community act at a micro level with other connections to institutions such as work, or health and social care provision acting at a meso level. Finally, connections to more over-arching political institutions and the discourses that occur in society offer a macro-perspective of influence on the carer (Pickard, 2010). These contexts will be discussed in detail throughout this literature review.

2.8 Caring Across the Life Course

It is possible to consider the carers of those with PD in terms of a life course perspective. This approach focuses on age and time (Elder et al., 2003). The interdependence of individuals with others and the resultant reciprocal influences and impacts that result from such interconnections is captured in the concept of 'linked lives' (Settersten, 2015). Thus, caring relationships are negotiated and evolve over time within families and with those from outside the family (Bengtson & Allen, 2009; Connidis & Barnett, 2019). For carers, their individual circumstances are influenced by their personal attributes, the era they were born, and the socio-political and economic context of their lives (Gilleard, 2004). Personal cultural beliefs and expected normative behaviours in society also affect how these ties are negotiated maintained and evaluated (Finch, 1989; Pickard, 2010). The agency of the carer is intricately bound to the structures they are located within. Thus, the choices and decisions taken in becoming a carer, are situated, and shaped by the wider structural components that intersect the carer's life. The agency within structure model (Settersten & Gannon, 2005) combines the influence of the wider macro socio-political and economic processes with individual experiences and biographies.

Within the life course perspective consideration is given to trajectories, transitions, timing and turning points. As the long-term trajectory of the life course unfolds time related events such as births, deaths and marriages occur that may be expected transitions and turning points (Elder et al., 2003). However, at other points unexpected events such as ill health or death may mark turning points in the pathway. Individual roles or status throughout the trajectory may relate to family relationships although multiple pathways are possible that relate to not only the family but to other societal institutions such as work and education. Thus, individuals may have multiple roles (e.g., child, parent, sibling, employee, and carer). At any time, institutional structures including education, social care, welfare and healthcare provision alongside employment policies and opportunities all have institutional effects on the carer through their intersection with salient social categories such as age (reflecting the era of birth), class, gender, sexuality and race (Dannefer, 2003; Settersten & Gannon, 2005). These intersections further impact on the expectations and available choices for carers and care recipients (Solimeo, 2009; Steverink et al., 2001). Furthermore, in

the 21st Century significant demographic change associated with longevity, the greater participation of women in the workforce, alongside austerity and increasing care costs are further shaping the demands for elderly care. This is directly impacting on the experience of contemporary informal carers in terms of the timing, duration, and nature of the care they will provide (Brimblecombe et al., 2018; Pickard, 2015).

The life course care is institutionalised (Keating & Eales, 2017), with differing expectations, and requirements for care at different stages of life (Fast et al., 2020; Nolan et al., 1996; Pearlin & Aneshensel, 1994) and variations across different cohorts (Moen & Spencer, 2006). It has also been argued that despite the changing roles of men and women during the 20th Century, those entering the third age of life (post retirement) experience ambiguity in their roles as they age and their experiences of care and their expectations of this stage of life do not align with societal changes and evolving policies (Fast et al., 2020; Pickard, 2010). Throughout their life women continue to follow gendered expectations in terms of their caring roles within the family (Finch & Mason, 1993; Ungerson, 2000). Even in the later stages of the life course, those influences, and expectations from earlier periods of life and the lifelong dynamics of interdependent family relationships will continue to influence the decisions taken in relation to caring (Gilleard, 2004; Moen & Spencer, 2006). Thus, social norms and structures in relation to caring (both informal unpaid care and formal paid care) influence those that provide care and lead to a predominance of women within caring roles (Barnes, 2012; Ungerson, 2000). Furthermore, predominant societal norms continue to promote that unpaid care as provided by the family is the best option for care-recipients and society (Finch, 1989; Finch & Mason, 1993; Twigg & Atkin, 1994; Ungerson, 1983; Ungerson, 1990, 2006; Yeandle et al., 2012).

2.9 The Caregiver Career

The interdependence of family life means that becoming a caregiver may be an unexpected event (a turning point) or occur gradually over time as life transitions (Nolan et al., 1996; Pearlin & Aneshensel, 1994). Carers often juggle competing obligations to others which may include their spouse/partner, children, parents, and employer (Egdell, 2012b). The 'sandwich generation' of carers (Brody, 1981; Miller,

1981) is growing as those (predominantly middle-aged women) with caring roles for children also take on caring responsibilities for ageing parents often while still in employment. Leinonen's (2011) research with Finnish adult child carers found that the relationship between adult children and parent(s) or the relationships among the siblings were all central to the allocation of caring duties. Although various rationales were offered to account for differential sibling responsibilities (such as different childcare and employment commitments), pivotal was the mediating role of relationships with the lives of the family carers linked to those of other actors involved in a care relationship.

Work that focussed on the carers of people with Alzheimer's disease/dementia by Aneshensel (1995) and Nolan et al. (1996) led to the development of conceptual frameworks that aim to capture the stages of caregiving. Although it should be noted that these were small scale studies. These both recognise the temporal dimensions of care and relate to the transitions that occur as the role evolves and ultimately ends. Both aimed to examine key points in the carer's career that might usefully enable direct support where needed. Table 2 outlines the key stages associated with each model. More recently Fast et al. (2020) have described five care trajectories that were identified from a latent profile analysis of over 3000 carers. These were as follows: compressed generational, broad generational, intensive parent care, career care and serial care. Age of first caring experience, number of years caring, number of episodes and total years of caring alongside any overlap in the different episodes were analysed. The variations described further highlighted the diversity in the life course patterns of care that can occur.

Finally, the consequences of caring over time due to the situational exigency of the situation can lead to longer term detrimental effects on the carer's future life course including their health and finances and reduced social contact (Keating & Eales, 2017; Pinquart & Sörensen, 2003; Abendroth et al., 2012; Hounsgaard et al., 2011; Williamson et al., 2008). These outcomes have led Public Health England (PHE, 2021) to argue that caring should be considered as a social determinant of health

Table 2 The Stages of Caregiving

Nolan (1996)	Aneshensel (1995)
Stage 1 Building on the Past	Stage 1 Role Acquisition
Stage 2 Recognising the Need	
Stage 3 Taking it on	Stage 2 Role Enactment
Stage 4 Working Through It	
Stage 5 Reaching the End	Stage 3 Role Disengagement
Stage 6 A New Beginning	

2.10 The Work of Chronic Illness

In examining the sociology of health and illness, the changing demands that are brought about in managing a long-term condition such as PD and the ‘work’ associated with chronic illness has been explored. This illness work falls not only on those with PD but also on their carers and others in the wider networks of support (Hand et al., 2018; Oguh et al., 2013; Knowles et al., 2016; Vassilev et al., 2013). Corbin and Strauss (1985) through in-depth interviews with carers and their spouses (each had a long-term or potentially life-limiting illness or condition) conceptualised that the everyday management of chronic illness could be divided into three lines of work; illness work; everyday work, and biographical work. Vassilev et al., (2013) have extended the biographical dimension to include emotional work associated with offering comfort, social companionship, and support for health and well-being matters. This can be framed within the ‘illness trajectory’ which captures this ‘work;’ how it impacts on the relationships of those with the illness and their carers; and its effects

on managing the on-going disease and the outcomes for those with the condition (Schneider, 2009). The work associated with the illness relates to those activities that are required to manage the condition, such as medicine management, monitoring and interpreting symptoms or measurements, and co-ordinating medical and other associated appointments. Everyday work relates to a range of routine activities and roles including childcare; occupational work; personal care such as washing and dressing, exercise, and diet; and tasks associated with managing a household such as shopping, preparing food and household repairs. (Vassilev et al., 2013, Corbin and Strauss, 1985).

Considering the concept of biographical disruption that is wrought at diagnosis or as an illness progresses, also allows an examination of how biography is shaped and affected by illness (Bury, 1982; Bury, 1986; Charmaz, 1983; 1995). Both Bury and Charmaz have described the process of diagnosis or the actual point at which the diagnosis is revealed, can have a significant effect on a patient's biography and acting as a symbolic marker or turning point. Thus, diagnosis acts as a critical point in the illness trajectory. For those with the diagnosis of PD this can be a point of 'experiential incoherence' as described by Pinder (1992, p.1).

Diagnosis and the development of a chronic illness finds the individual, and those who support them, begin a process of negotiation as the 'work' to manage the condition or illness becomes apparent and evolves over time (Corbin and Strauss, 1985; Vassilev et al., 2013; Solimeo, 2009). However, Solimeo (2009), noted that although those with PD recognise that it is incurable and progressive, many did not identify themselves as sick. For many it was 'embodied as a condition with which they lived and aged' (p.14). The individual's social location, age, culture, and somatic body intersect to shape their embodiment of the disease, and the process of making sense of their physical decline in relation to the PD diagnosis were apparent in their construction of the disease and their experiences. Therefore, the interplay of the processes of ageing and the disease progression associated with PD was a complicated one which required an ongoing reflexive narrative that sought to extricate the two but recognised that both were leading to decline. This aligns with the concept of biographical flow as a means of understanding illness as part of life's biography (Faircloth et al., 2004). For some this can be integrated with various social contingencies to construct an on-going biography

that can 'flow across time and space' (p 256). Age, other co-morbidities and previous understanding and knowledge of the condition all influence the biographical impact. Furthermore, illness does not necessarily result in biographical disruption. Thus, identity is dynamic as it continues to be constructed across the life course and the illness trajectory (Charmaz, 1995; Settersten, 2015). It is dependent on social contingencies, the interaction between individuals, the somatic manifestations of the disease, the social context, personal biographies, and resources. The illness trajectory can therefore be shaped by social mores as much as the physical manifestations of the disease (Nijhof, 1995; Charmaz, 1983, 1995; Solimeo, 2009).

Emotional work is an integral part of caring but can remain invisible and neglected (Hochschild, 1983; Smith, 1992). Care was conceptualised by Graham (1983) as having two dimensions, that of both labour and love. As described in the introductory chapter, care has an instrumental component, caring for, and the emotional component in caring about (Ungerson, 1983). Although aspects of everyday work and illness work can be measured and quantified, emotional work is less tangible. For carers of those with PD dealing with physical and cognitive changes can have a significant emotional impact (Aarsland et al., 1999; Williamson et al., 2008; Mc Loughlin et al., 2011). Carers of those with psychosis (a symptom that can occur as PD progresses) use emotion-focussed strategies to minimise and facilitate acceptance of the changes that were occurring through downward social comparisons (Thoits, 2011) in relation to others with PD (Williamson et al, 2008). In dealing with biographical changes, Lindgren (1996) found that some carers of those with PD experienced chronic sorrow, as they grieved from losses experienced through the illness trajectory. These were often related to manifestations of PD such as falls and other signs of disease progression. The affective dimensions of relationships within families are complex (Bengston, 1991; Phillipson, 2001; Connidis and Barnett, 2019;) and the sharing and display of emotions can be subject to 'normative guidelines' (Finch, 1983: p 207). Consequently, shared biographies, and varying contributions to the management and organisation of care can lead to heightened emotions with conflict, tension, and ambivalence between those in the network (Amaro, 2017; Carpentier & Ducharme, 2005; Hillcoat-Nallétamby & Phillips, 2011; Leinonen, 2011; Tolkacheva, et al., 2011). However, there is growing evidence that for carers and their care-recipients, peer support groups are part of those wider networks that can offer

emotional support for those with a long-term chronic condition (Abendroth et al., 2014; Vassilev et al., 2013; West & Hogan, 2020).

Utilising a network approach, Vassilev et al. (2013) surveyed 300 people each with a chronic illness to identify key alters in their network who offered support with the work of illness self-management. Partners and close family gave the most contributions, other relationships were evident that also offered support with illness work. A degree of substitutability across the network particularly when partners were not available was also apparent. In an extension of this approach, 19 informal carers were interviewed, and the data was examined in terms of the illness work the carers undertook (Knowles et al., 2016). The findings primarily demonstrated that carers engaged in biographical and emotional support work. As found in other work (Cavaye, 2006), there was a sense that carers deliberately minimised their role to prevent identity disruption for the care-recipient and to maintain their independence and wider-family relationships. Thus, for some there was a resistance to identify as a carer or to legitimise their caring role.

2.11 The Social Networks and Social Capital of Carers and Older People

The social networks and ensuing relations that carers and older people develop through the life course have the potential to support and assist them and develop into networks of care (Connidis & Barnett, 2019; Egdell, 2012a; Keating et al., 2003; Sims-Gould & Martin Matthews, 2007). The resources and associated dynamics of these social relationships can offer positive benefits that can aid those in the network (Bowling, 1994; Christakis & Fowler, 2009; Fabrigoule et al., 1995; Keating & Dosman, 2009; Keating et al., 2005; Personal Social Services Research Unit, 2010; Putnam, 2000; Roth, 2020; Wenger, 1993; 1997). The provision of informal care takes place in networks comprising of families, friends and the wider community and it can be supported by formal care in the form of health and social care services. More recently the role of social networks and the resources within them are beginning to be recognised by the health and social care sectors as having a potentially important role in the management of long-term conditions for service users and carers. Understanding the role of social networks in terms of how service users and carers

manage a long-term condition has implications for care provision and has the potential to improve care networks through working in partnership with service users and their carers (Christakis & Fowler, 2009; Vassilev et al., 2011; 2013; 2014)

The focus of this work is to examine the informal and formal social networks and the concomitant social capital of those caring for somebody with PD in the UK. Using social network analysis, it is possible to ascertain the structural elements of the carers' networks and their functionality in terms of how support and aid are provided to the carer. However, the study will also examine the relational properties and dynamics within the networks. By analysing these social relations and interactions it is possible to extrapolate social phenomena and gain greater understanding of the intricate interactions of the carers and those who formed their informal and formal care networks (Borgatti et al., 2009; Hollstein, 2011). The relational dimensions within the networks have the potential to impact on the access and provision of resources within those networks. These interactions can vary according to the gender of the carer (Rodríguez-Madrid et al., 2018; Sanders, 2007), their ethnicity (Katbamna et al., 2004) the nature of the familial relationship (Amaro, 2017; Dam et al., 2018; Jacobs et al., 2016; Leinonen, 2011); and the involvement of friends and neighbours (Lapierre & Keating, 2013). The interactions and dynamics across the informal and formal network can also influence the provision of aid and support (Carpentier & Grenier, 2012; Groen-van de Ven et al., 2018; Jaglal et al., 2007; Sims-Gould & Martin-Matthews, 2010). In a meta review of the effects of support interventions, contact with those outside the carers' informal networks (whether it be professional contact or with other carers) may viewed as beneficial, regardless of how it was achieved (Thomas et al., 2017).

2.12 The Concept of Social Capital

In considering the social, support and care networks that the carer is located within, it is possible to then examine how these may act as a source of social capital. The concept of social capital proposes that society is comprised of social networks and structures that link individuals in complex and meaningful ways. Within these social structures and networks are shared understandings and norms of behaviour that

shape interactions, co-operation, and society (Halpern, 2005; Portes, 1998; Putnam, 2000, 2004). The nature and extent of these social relationships form assets or capital that can be leveraged or utilised for material gain (Coleman, 1988; Granovetter, 1973, 1983). The notion that social networks and their associated norms of behaviour are a form of capital and therefore act as a fungible commodity that can provide returns is central to understanding social capital (Halpern, 2005). Furthermore, it is argued that such returns can benefit individuals, communities, and society. Hence, it has comparability to other forms of capital such as financial or physical capital (Field, 2008). It is argued that this offers a socio-economic approach to both public health and wider policy agendas (Baum, 1999; Portes, 1998).

2.12.1 Social Capital: Origins and Development

Work from the 19th Century offered some of the earliest understandings about the nature of social relations and their effects on individuals. Durkheim examined rates of suicide and found that where individuals were well integrated into society suicides were less frequent. From this work Durkheim emphasised that members of society are united by 'ties' and that individual behaviour could only be understood in considering the community and the relationships within those communities (Durkheim & Halls, 1984)

Bourdieu argued that individuals or agents within the social field have access to different forms of capital that they may utilise to maintain or improve their position or standing within society. Bourdieu envisaged three forms of capital including the established view of economic capital but also developed arguments for cultural and social capital. Although his work focussed principally on cultural capital, examining how cultural symbols may be used as marks of distinction and as means of maintaining social hierarchies, he also developed his own definition of social capital.

Social capital is the sum of resources, actual or virtual, that accrue to an individual or group by virtue of possessing a durable network of more or less institutionalised relationships of mutual acquaintance and recognition (Bourdieu & Wacquant, 1992, p. 119)

In exploring the concept of social capital (and other forms of capital) Bourdieu proposed that these are acquired within social fields. These fields can be located at the micro, meso and macro-level of society such as those found within networks of care (Angus et al., 2005; Collyer et al; 2015; Collyer et al., 2017; Bourdieu, 1986; Bourdieu and Wacquant; 1992; Bourdieu, 2007). They are structured systems of social positions which can be occupied by individuals or institutions in the field. Power relations and differentials exist between those network structures, and this can determine access to the capital within that field. To explain how actors operate within the fields, Bourdieu uses the concept of habitus which is defined as a set of general generative schemas or dispositions acquired over the life course (thus encompassing a generational or collective history). These are applied in varying social structures or fields and shape the practice and logics of the field (Angus et al., 2005; Bourdieu, 1992; Bourdieu, 2007).

In America James Coleman was also drawing on economics and sociology to develop his theoretical understanding of the concept. Coleman's work particularly focussed on social inequalities and educational achievement in American schools (Coleman, 1988). His work was underpinned by rational choice theory (where individual actors pursue their own self-interests) and in defining social capital he viewed it as complementary to the development of human capital. He defined social capital as follows:

Social capital is defined by its function. It is not a single entity but a variety of different entities, with two elements in common: they all consist of some aspect of social structures, and they facilitate certain actions of actors-whether persons or corporate actors-within the structure. Like other forms of capital, social capital is productive, making possible the achievement of certain ends that in its absence would not be possible. Like physical capital and human capital, social capital is not completely fungible but may be specific to certain activities. A given form of social capital that is valuable in facilitating certain actions may be useless or even harmful for others. (Coleman, 1988, p. S98)

The most prominent recent proponent of social capital has been Robert Putnam who examined the nature of social capital in Italy (Putnam et al., 1993). His work in Italy measured social capital in terms of participation in 'horizontal' associational

organisations such as choirs and levels of reported trust between strangers. Where participation and trust were high (generally in the north of Italy) Putnam found that local Government was more effective and cohesive. More recently he argued that there had been a decline in social capital within America since the post war period. This was discussed in his work *Bowling Alone* (Putnam, 2000). This charted the decline of civic life within the USA. Retrospective data was used (particularly the General Social Survey, GSS, the National Election Studies, the Social and Political Trends survey and the DDB Needham Life-Style Surveys) alongside records detailing membership of national bodies. From this Putnam found a steady decline in political and religious participation, associational membership, volunteering, charity work and socialising through work with a reduction in informal networks. Putnam formulated a Social Capital Index (using separate measures of social capital such as social trust and civic engagement) to analyse the data state by state. Critically, in this work he argues that where social capital is depleted (particularly in the southern states of the USA), indicators of well-being are also diminished.

In examining social capital Putnam has presented several iterations in his definition of the term and has argued for a pithier definition of social capital, as follows:

social networks and norms of reciprocity (Putnam, 2004, p.668).

Although there is much debate about the varying aspects of social capital, Halpern (2005) and Ferlander (2007) argue that there are several dimensions as follows:

- Several components that include networks, norms, and sanctions
- Differing levels; individual, meso (community) and macro (national)
- Differing functions which are, bonding, bridging, and linking

2.12.2 Networks, Norms and Sanctions

Social networks surround individuals and exist within communities or neighbourhoods. The nature and extent of these networks may vary and may not necessarily fall within distinct geographical areas (Rowson et al., 2010). Rules and values within the

community and the networks will determine how social norms and sanctions operate and can have both behavioural and affective or cognitive components. Trust is viewed by some as an integral component of social capital whereas others view trust as an outcome of social capital (Office for National Statistics (ONS), 2001). It is argued that trust within relationships and dealings with others facilitate and ease transactions between individuals (and more widely across communities or a society). Fukuyama (1995) has examined this from an economic perspective and argues that the inherent trust within a society (as a component of social capital) can aid and increase economic performance. To sustain social capital, trust alongside recognised norms of behaviour and reciprocity are therefore viewed as requisite features (Lin, 1999; Putnam, 2000). Furthermore, these are viewed as not being independent of social relationships but are nurtured within the context of a relationship (Woolcock, 1998). For many the structural component of social capital, i.e., social networks, forms the core of the concept with participation in the network as a central feature. In Bourdieu's (1986) analysis, he focuses on this and describes it as follows; 'actual or potential resources which are linked to possessions of a durable network' (p.248). As for norms of reciprocity, Ferlander (2007) relates this to forms of exchange associated with social support. Social support is viewed as the principal means that individuals and household can obtain resources although Wellman and Wortley (1990) consider that such exchanges 'transcend narrow reciprocity' (p.559). If social support is a resource residing in or accessed via networks others view such resources that flow within networks as forming the social capital (Burt, 1992, 1997; Lin, 1999).

Portes (1998) has identified the potential negative consequences of social capital through downward levelling of norms, restrictions on individual freedoms, excessive claims on group members and exclusion of those outside the group. Where there are close social relationships supportive behaviours and actions can become difficult since they may be excessive to what is needed or desired and may create negative feelings for the recipients (Boutin-Foster & Charlson, 2002). Dominguez & Watkins (2003) examined the social networks of low-income mothers and found social mobility can be reduced by group enforced 'time- consuming and professionally limiting expectations on women' (p.111) particularly where the size and heterogeneity of the network is reduced and there are already existing tensions within the network.

2.12.3 Levels of Social Capital

Social capital can operate at varying levels within society. Unlike Bourdieu (1986) who emphasised that social capital is principally an attribute of an individual, Putnam (2000) considers this to be a wider property of communities.

At the individual level, relationships developed with others through various activities (e.g., leisure, political activism work, membership of a church or local group) offer a means of gaining access to resources (such as information, money, or practical help) that can be utilised and enhance the life of the individual. Interestingly, using data from the European Social Survey (a large survey of 22 countries, N = 42,358), Poortinga (2006) found that social capital was principally beneficial at the individual level and individual levels of social trust and civic participation were strongly associated with self-rated health. Whereas at the national level the aggregate social trust and civic participation variables were not related to people's subjective health once compositional differences in socio-demographics were controlled for. Portes (1998) argues that the empirical potential of this concept lies at the level of the individual since he argues that the concept of social capital is not refined enough to be applied more widely. Edwards and Foley (1998) also view this as a social-relational concept for the examination of social networks and organisations.

Some have difficulty with the individual definition since it is argued that this approach tends to focus on an individual's social network structure and their access to assets within that structure such as social support (McKenzie & Harpham, 2006). Kawachi et al. (2004) view this as not advancing the concept of social capital but instead returning to previous network and social support approaches. However, Lin (1999) argues that social capital is captured from embedded resources within social networks. This is also aligned with Bourdieu (1986) who proposes that two components form social capital; the first being access to resources from those who are part of an individual's social relationships and secondly the amount and quality of resources that reside within those relationships. This view of social capital stresses the fungibility of the various forms of capital.

Lin (1999) argues that an individual's engagement and interaction within a network can produce gains since the embedded resources in the network can enhance

outcomes. He argues that this works at an instrumental and expressive level through the following: flows of information, personal influence, social credentials or standing and reinforcement of one's personal position. At an ecological level (be it meso or macro level approaches), aggregations of individuals' social capital become the key to ascertaining the benefits and outcomes for a community or nation (Halpern, 2005). The communitarian approach principally advocated by Putnam (2004) and Fukuyama (1995) equates social capital with high levels of trust within a society alongside a vibrant civic life including membership of local organisations and clubs. Both would argue that these factors equate with increasing levels of social capital that has wide-ranging benefits for communities and nations. Increasingly a more pragmatic approach is being taken with commentators recognising that each approach is not mutually exclusive (Ferlander, 2007; Halpern, 2005). Lin (1999) proposes that interactions ensure that social capital as an asset is reproduced, and this can be at a meso or societal level or at a relational level between individuals.

2.12.4 The Functional Forms of Social Capital

Distinctions have been made between the functional forms of social capital since it has been recognised that networks can and do have different features and potential consequences (Putnam, 2004). Bonding social capital is usually exclusive and is characterised by strong bonds, examples might include networks within a family or among members of an ethnic group. Bonding social capital is often associated with personal support and close friendships (Ferlander, 2007). However, bridging social capital is more heterogeneous and associated with weaker network ties that span or cross individuals of differing, age, race, and social class. This is viewed as more inclusive in nature. This type of social capital is believed to be important for social mobility and facilitating the sharing and exchange of information through diverse social networks (Granovetter, 1973, 1983). In Granovetter's (1973) empirical work he found that weak ties were more useful in helping people find work. Burt (1992) has also commented on those individuals who occupy 'structural holes' within networks can 'tie' or link separate social networks. These individuals are often pivotal in the transference of information and ideas across a diverse group.

Finally, linking social capital has been described as those networks that connect individuals in society that are in different hierarchical positions (for example within work organisations) or have different levels of institutional power (for example, the politician and the public or the health professional and the client) (Szreter & Woolcock, 2004). Although Putnam (2004, p.669) expresses some ambivalence regarding this distinction he does acknowledge that if there is trust and respect in such relationships it 'could underpin policies and practices to foster social justice and public health.'

2.13 Quality of Life and the Social Capital and Social Networks of Older People

The social capital and social networks of older people have been examined in relation to changing demographics and on-going shifts in social policy (Gray, 2009a; Wenger, 1997). For some time, there has been a recognition that empirically there is a relationship between social support, network features and health status, mortality, and increased risk of requiring longer term residential care (Bowling, 1994). Fabrigoule (1995) examined the relationship between social and leisure activities and risk of subsequent dementia in a prospective study of community residents (65 years plus) in France. Regular participation in social or leisure activities were associated with a lower risk of subsequent dementia. In the UK, the 2010 evaluation of the Partnership for Older People Projects (POPPs), (a project designed to promote health and well-being), concluded that investment in community development for older people produces significant gains in quality of life and financial benefits (Personal Social Services Research Unit (PSSRU), 2010). It appears that social support facilitates older people to remain at home for longer, sustain their quality of life and friendships whilst maintaining their cognitive function. Examining social support as an outcome of social capital, Gray (2009a) found that in those aged over 60 years who were childless or had been continuously without a partner had poor support. Whereas those who had frequent contact with others and interacted with their neighbourhood and viewed it positively, had good support. In this study, social contacts appeared to have more of an effect on social support than activity in local organisations.

2.14 The Relational Dimensions of Carers' and Care Recipients' Networks

Although the carer-care recipient dyad has been a focus for research and analysis of caring relationships some consideration has also been given to the wider social networks that the carer and care-recipient are located within. It is argued that a greater focus is needed on the individuals involved in the care network not only the structural links that bring them together (Fast et al., 2004; Sims-Gould & Martin Matthews, 2007). Support networks are derived from this wider pool of individuals and the potential interactions that are supportive in this way may be considered as 'social support.' (Fast et al., 2004). Thoits (1995, p. 64) defines social support as 'functions performed for the individual by significant others such as family members, friends and co-workers.' These functions typically include emotional aid, instrumental aid, and informational aid (House et al., 1988). Thoits (1985, p. 2011) has further proposed that there are several mechanisms through which social support may improve physical and psychological wellbeing: social influence/comparison, social control, role-based purpose and meaning (mattering), self-esteem, sense of control, belonging and companionship, and perceived support availability. The ties providing this support are strong, long-standing, and typically comprise close kin and friends (Peek & Lin, 1999).

The positive effects of supportive interactions are classified in two ways. The stress buffering effect is apparent in times of crisis when there is a real need for support. However, it is recognised that the wider, more significant effects of personal relationships on overall well-being (the 'main effect') is in knowing that there is a network of support that can be called up on in times of need (Cohen & Wills, 1985; Thoits, 1985). As such, in trying to delineate support networks it is important to draw on the potential supportive nature of any relationship. Wenger (1997) from a longitudinal study of elderly people in North Wales and using both qualitative and quantitative data, formulated a typology of five different types of networks (see Table 3). From the study Wenger found that elders depended mainly on family members for personal care and advice on personal problems. However, friends and neighbours were important for other types of instrumental support such as accessing a lift or borrowing small items (Wenger, 1997).

Table 3 Wenger’s (1997, p.313) Typology of Support networks

Type of Network	Features
Locally integrated support network	Most common and most robust support network. Informal help to and from local family, friends, and neighbours. Involvement in community groups.
Wider-community focused support network	Absence of local kin. Informal help to and from friends; some involvement with neighbours; contact with family more than 50 miles away. High level of involvement in community groups.
Local self-contained support network	Reliance primarily on neighbours, but involvement of kin more than 5 miles distant. Privatised lifestyle. Involvement with community groups low key.
Local family dependent support network	Reliance on local family; some neighbour contact. Low levels of community group involvement.
Private restricted support network	Absence of local kin. No local source of informal support. Little contact with community. May rely on distant kin.

Where long term health conditions are present or in deteriorating health or increasing frailty, those in the network may increase or extend the range of support given particularly in relation to instrumental and emotional aid. Care is different in its form and intensity from what may be expected in everyday life (Fast et al., 2004). This transition from support to care may be gradual and evolve over time or may occur suddenly in times of crisis. Such care networks are often smaller, less diversified and can be more fragile (Fast et al., 2004; Keating et al., 2003; Wenger, 1997). The point at which health and social care services enter the care network will vary and will be influenced by the resilience of the formal network, and the recognition and acceptance of outside support (Carpentier et al., 2008; Cavaye, 2006).

The structuring of any formal support will vary and be influenced by the choices made by the carer and care-recipient alongside the availability of and eligibility for services that can meet the needs of the care-recipient and carer (Carpentier et al., 2010; Carpentier, et al., 2008; Carpentier, Pomey, et al., 2008; Egdell, 2012a; Hong, 2009). To examine the intricacies of informal and formal care provision and the intersection of the two it is necessary to consider the impact of several inter-related factors (Moen

& DePasquale, 2017). The financial constraints and austerity measures of the last decade (Glendinning, 2012; Humphries et al., 2016); the growing care gap (Brimblecombe et al., 2018; Pickard, 2015), and family demographic changes that impact on the availability and propensity of the family alongside friends and the wider community to provide care (Keating & Eales, 2017; Silverstein & Giarrusso, 2010) will be considered in the forthcoming sections. To understand the nature of the relationships and dynamics that exist between the informal and formal providers of care, consideration will also be given to the influence of the evolving policy landscape and the significant changes to the ethos and structures associated with health and social care delivery.

2.15 Informal Care: Family and Non-Kin Support of the Older Adult

Although caring often takes place within family structures, greater pluralistic models of family life are emerging. The form and complexity of this network is unique and will be heterogeneous since it has evolved through the life course and is dependent on structural, social, and cultural contexts (Connidis & Barnett, 2019), with the family described as a 'microsocial group within a macrosocial context' (Bengtson & Allen, 1993, p. 47). Individuals with shared biographies interact over time and space through evolving social contexts (Dannefer, 2003; Settersten & Gannon, 2005) and this impacts on the expectations and available choices for carers and care recipients in terms of giving and receiving care (Solimeo, 2009; Steverink et al., 2001). Informal support of the older adult includes a range of help that may include emotional support to practical aid or personal and intimate care (Connidis & Barnett, 2019; Thoits, 2011). Changes in physical and psychological health resulting in a decline in health status determines the requirement for support and care (Carpentier & Grenier, 2012; Hong, 2009). Those closest to the individual in decline will often note and observe early manifestations of a disease process and this can determine how wider more formal support is triggered (Carpentier et al., 2010). Most care for older vulnerable adults is provided by relatives. However, those involved, the nature of the care provided and the division of responsibility across the family will vary. Spousal care is usually the predominant choice followed by adult children (Pickard, 2008).

2.15.1 Changing Family Demographics and Care

Changing family structures are beginning to challenge expectations of filial responsibility and potentially may alter the number of kin available able and/or willing to care for the growing elderly population. Although much of care of the elderly in the community continues to be provided by kin societal changes are impacting on the availability and involvement of different family members (Broese van Groenou & De Boer, 2016; Roberto & Blieszner, 2015). During the late 20th Century and into the 21st Century significant socio-economic and demographic shifts associated with an increasing ageing population, increased numbers of women in the workforce alongside altered employment patterns and greater geographical mobility and migration, have challenged how the care needs of the elderly and those with long term conditions can be met. Furthermore, there has been a growing acceptance of the ideological shift to autonomy and control over individual lifestyle choices and the ways in which people live their lives (Allan, 2008). These changes have impacted on personal relationships and how individuals construct and maintain these relationships be it with family or friends (Pahl & Pevalin, 2005; Pahl & Spencer, 2004).

The networks formed from family and kinship structures have evolved and become more fluid and dynamic over time. This fluidity involves an 'interplay of intertwining lives' (Riley, 1983, p. 446). These interactions and the support they provide can depend on many inter-related factors. Given that the conventional model of nuclear family life is transforming, and more pluralistic models are emerging the availability and propensity of kin to care is also potentially changing. Changes and trends associated with marriage, divorce, cohabitation, and childbirth illustrate a divergence from the previously accepted structured phases of the life course (Allan, 2008; Broese van Groenou & De Boer, 2016; Keating et al., 2015; Roberto & Blieszner, 2015). Thus, it can be argued that there is now greater flexibility in choice and control over how partnerships are constructed since they have become less socially prescribed than previously (Allan, 2008; Pahl & Spencer, 2004). The ageing demographic and reduction in birth rate is giving rise to 'beanpole' families (Connidis & Barnett, 2019; Roberto & Blieszner, 2015) with the elderly heading a vertical family of potentially multiple generations. This has the potential to place demands on the middle generation as they balance the care of their elderly relatives with their own childcare or that of their grandchildren (Brody, 1981; Miller, 1981). Thus, intergenerational

relationships are increasingly important as the population ages with the resultant increased longevity of senior family members and a longer period of 'shared lives' across the generations. This allows the opportunity for an increasing role of grandparents and other kin in family functions. Divorce and remarriage with an increase in stepfamilies also adds to the diversity of the multi-generational structures (Bengtson, 2001).

The ONS (2011) census data indicated that more informal care in England and Wales is provided by women (58% vs 42%, ONS, 2011). Women are projected to continue to be the main providers of care (over 60%) by 2032 and are more likely to provide intense intergenerational care than men (Pickard, 2015). Thus, although demographic shifts are beginning to increase the numbers of men who are caring, informal caring will continue to be predominantly the role of women. Finch and Mason (1993, p. 124) in their work argued that 'gendered biographies can mean that women, unlike men, are viewed as being in a position which makes them able to juggle various commitments simultaneously without the need to prioritise one over another.' Furthermore, the legitimacy of women's commitments has less importance than those of men. There is uncertainty in relation to the numbers of children who in the future will be able to provide informal care to their parent(s). Modelling to project the supply of unpaid care for parents aged 65 and over in England by Pickard (2015) and further modelling by Brimblecombe et al. (2018) that consider demand to the 2030s have both predicted that there will be a shortfall of supply, 'a care gap' with the demand for care of older people exceeding that available from informal care. From an intergenerational perspective although family sizes are decreasing improvements in mortality rates across all cohorts will mean more elderly people in the future will have a surviving child who potentially may provide care (Silverstein & Giarrusso, 2010)

The propensity for children or others in the family, to provide unpaid informal care varies by individual circumstances. Broese et al. (2016) view the provision of informal care as a process that is context dependent and associated with the primary carers and care-recipient's individual and relational situation. In terms of the home or community setting (not within residential care or nursing care) the timing and decision to provide care can be related to several factors. For the caregiver, their individual disposition, based on both their willingness to become a carer, their normative beliefs

alongside individual constraints may impact on or preclude them from the role. Previous exchanges of help and support between individuals alongside a sense of obligation or expectation to provide care are influential in who may become the principal carer (Egdell, 2012b; Finch, 1989; Finch & Mason, 1993). A consensus between the carer and care recipient on the expected norms of reciprocity and solidarity are associated with an increase likelihood of informal caring (Bengtson & Roberts, 1991). In relation to child-parent care, Bengtson and Roberts (1991) proposed that there are six dimensions that encompass intergenerational solidarity i.e., the closeness of family bonds and their supportive outcomes over time. These are described as; affectual/affective, associational, consensual, functional, normative, and structural. These incorporate both behavioural and emotional dimensions of the relationship between parents, their children, along with grandparents and grandchildren. The strength of the affective/emotional bond and the frequency of contact (the associational dimension) can directly impact on the propensity to provide care as the parent ages. This concept of intergenerational solidarity was extended to recognise that conflict plays a part in family life, thus shaping how family members interact and support one another. The interplay of solidarity and conflict can be complex within a family dynamic with both existing at varying levels and dependent on family circumstances.

Ambivalence has also been introduced as a further dimension of family relationships (Connidis & McMullin, 2002; Luescher & Pillemer, 1998). Ambivalence is also a product of intergenerational relations, with the plurality of the modern family producing different forms and types of family which then impacts on relationships over time. Contradictions in the relationships between older parents and their adult children can exist at a structural level in terms of individual roles and expected norms, and at a psychological level, in terms of the emotional aspects, understanding, and motivation to provide care. Aspects of family life can generate ambivalence as tensions between dependency and autonomy between parents and adult children occur and as conflicts arise in relation to norms of reciprocity and solidarity when care giving is prolonged and stressful. In relation to intergenerational care, it has been found that care provided towards parents was associated with support received earlier in life. Thus, intergenerational exchanges over time can determine future care provision of elderly

parents by their children (Evandrou et al., 2018). In a nuanced study of care distribution by siblings for their parents, Leinonen (2011) identified three main approaches: absence; backup; and togetherness. Although childcare and employment commitments did affect involvement, family dynamics and relationships were key. Thus, participants stressed that 'either the relationship between adult children and parent(s) or the relationships among the siblings influenced the division of care duties.' (p.324).

Other barriers will impact on the ability or willingness to provide care. Declining co-residence of adult children with their parents and dispersion of families means that geographical distance will impact on caregiving in terms of availability, travel demands and the associated additional demands on time (Bell & Rutherford, 2013; Bowes, et al., 2020; Dawson et al., 2015). Time can also be a significant constraint particularly for those with other family commitments (e.g., childcare) and employment (Egdell, 2012b; Spillman & Pezzin, 2000). The increasing role of women in the workplace throughout their lives and particularly in mid-life will affect care provision in the future (Brimblecombe et al., 2018; Pickard, 2015). The financial impact of caring particularly on earnings have been examined and although state financial support to care can act as an incentive, it can also be a disincentive depending on circumstances, and so a trade-off can occur (Brimblecombe et al., 2018). Furthermore, the attitude of those from the baby-boomer generation, as they approach the demands of caring for their ageing relatives, may also negatively impact on care provision (Finkelstein et al., 2012).

Therefore, a final consideration regarding family care of the elderly are the cohorts that form the 'baby boomer' generation who were born in the mid-1940s to the mid-1960s. This group are now forming the ageing cohorts requiring care and those within families providing care. In 2020 the oldest baby boomer was 75 and the youngest 55 years old. The baby boomer generation navigate complex intergenerational structures; and decisions about support are influenced by their personal values, their family's needs, and their own personal rewards. Changes associated with divorce and remarriage appear to attenuate intergenerational obligations for some families with changing cultural norms also weakening family bonds (Fingerman et al., 2012). The concept of a 'generational habitus' has been proposed by Gilleard (2004, p. 115) that builds on Bourdieu's work considering how culture and structural features of particular

eras can influence and shape dispositions and practices (the habitus) of a generation (Bourdieu, 2007). Consideration of the baby boomer generation and their disposition to informal care is important, given that it currently has implications for the negotiation of family care, and will continue to do so in the coming years, as the later baby boomers age and become frail.

2.15.2 Care from Friends and Neighbours

The altered family structures previously described with increased geographical mobility and dispersion of families has led to an increasing emphasis on relationships with friends and neighbours (Pahl & Spencer, 2004). As such care may also involve friends and neighbours as the boundaries between friendship and family are increasingly blurred (Barnes, 2012). Suffusion is a concept that has been introduced to describe how family and friend relationships might overlap and blur (Pahl & Spencer, 2004). The notion of 'fictive kinship' is used to describe friendships that have become comparable and as important as co-sanguineous or filial relationships (Allan, 2008; Roberto & Blieszner, 2015). Such relationships have also been recognised as sources of care for older people (Ward et al., 2012; Wenger, 1993). It should also be noted that suffusion can also be applied to relationships within family members. These relationships might also have friendship-like qualities that extend beyond normative social obligations and blood ties to compatibility, liking and a more voluntary dimension within the relationship (Pahl & Spencer, 2004). Friends and neighbours have been identified in care networks (Fast et al., 2004; Keating & Dosman, 2009; Lapierre & Keating, 2013). Friends offer a greater range of support, whereas neighbours (given the geographical proximity) are more likely to support with home maintenance (Lapierre & Keating, 2013). The involvement of friends in the network has also been found to increase opportunities for bridging social capital to community resources (Keating & Dosman, 2009).

2.16 Care from the Wider Community: The Role of Third Sector Organisations

The significant role that voluntary organisation played prior to the formation of the National Health Service (NHS) in 1948, in funding and providing health and social support is well known. From the 1970s the development of the role of voluntary organisations and other similar social enterprises and mutual organisations (now termed Third Sector Organisations) (NAO, 2013), has been promoted to create partnerships between this sector and state provided health and social care. The coalition Government in 2010, at the start of the austerity measures emphasised voluntarism and self-help as part of the promotion of the 'Big Society' (Cabinet Office, 2010). The sector contribution is significant and its role in health policy has been acknowledged (Baggott & Jones, 2014; Curry et al., 2011; Evers, 1995; Wanless, 2004). These have identified that this sector can help in a myriad of ways to support and further community health and social care. The list of benefits are wide ranging and include: promoting self-help and self-care; campaigning and lobbying; providing information and promoting measures for disease prevention; enabling integration of services through their links with a range of varied providers; informing local and national policy whilst ensuring that service users, carers and marginalised groups can inform the planning and delivery of services; providing services that are developed and bespoke for their users' needs and raising funds for research. The 'polyvalent role' (Evers, 1995, p. 159) that these organisations have and their position as an intermediary between the various structures that form care can be viewed as offering a buffer between the state and the market when it comes to care delivery (Moen & DePasquale, 2017). This sector offers a source of real support for those with long-term conditions and 'hard to reach' groups (Flanagan & Hancock, 2010; Morris et al., 2015). Evidence is now demonstrating that many areas within the Third Sector provide resources that complement traditional medical and self-management approaches of long-term conditions. These can also address broader social issues that can impact on an individual's capacity to manage their condition. The support can be varied and may have social, affective, and instrumental components (Abendroth et al., 2012; Morris et al., 2015; Teahan et al., 2020; West & Hogan, 2020)

2.17 Formal Care: The Marketisation of Health and Social Care

Before the 1980's, the provision of care for the older person was viewed as a Cinderella service with a low priority and little strategic vision or urge to reform and evolve services. Residential services (often in long stay 'geriatric' wards) or basic community care was provided if the family could not meet the needs of the older person. However, during the 1980s and 1990s there became an increasing concern regarding the economic sustainability of providing formal institutional care as the UK population began to age. Governments and policymakers began to forecast the future needs of the pre-war generation and the post war 'baby boomers' into the millennium and beyond. Thus, alternatives to publicly funded long-term institutional care were sought to reduce costs to the state. This resulted in a shift to greater levels of domiciliary care with a concomitant desire for 'deinstitutionalisation' (particularly in mental health services) and a quasi-market economy (Le Grand, 1991).

A significant catalyst and driver of these changes was the NHS and Community Care Act (1990). This introduced the quasi-market for health and social care services. In adult social care a greater pluralistic approach to care provision through a purchaser-provider split began. In this quasi-market the state acted as the purchaser for the 'consumers' of health and social care i.e., service users and their carers. Thus, a mixed economy of care evolved (Glendinning, 2012). This approach was viewed as a cost-effective and efficient approach to the delivery of a range of services (Le Grand, 1991). As a result of this legislation, outsourcing of services (through a process of competitive tendering), saw many council-owned care homes taken over by the voluntary and for-profit sectors. This included services such as residential care, day centres and home helps. In the 1980s, over 80% of adult residential care was provided by the public sector, but by 2015, the NHS or local councils provided less than 10% of social care. The private sector held the majority share (74%), voluntary providers accounting for 18% and public providers just 8% (Barron & West, 2017). From the 1980's the voluntary sector has evolved into a formal welfare provider with an understanding of the needs of the local communities and particular client groups they have been associated with. The potential for flexible and cost-efficient means of providing care has been an attractive option. Over 90 per cent of actual support is provided by a multitude of independent organisations (Humphries et al., 2016). These organisations

cover large corporate institutions to small family-run businesses. The management of this 'mixed economy' is not without difficulties (Glendinning, 2012). The voluntary sector has traditionally held values based on the UK's long history related to the Civil Society i.e., charity, volunteerism, mutual help, and advocacy (Savage & Pratt, 2013). Changes in funding streams as charitable donations have decreased due to austerity and an increasing reliance on statutory funding (which has also diminished) obtained through grants and successful tendering processes has led to a reduction in the number of viable organisations. Furthermore, concerns have also been raised that the ability of these organisations to advocate has also been compromised in their need to win Government or Local Authority (LA) contracts (Savage & Pratt, 2013).

The combination of demographic change with an ageing population and the move from institutional care has meant that greater numbers of older people in need have remained at home. Thus, there are increasing numbers of households containing frail, aged individuals. The goal of provision is to aid independent living to protect those who are vulnerable, to assess risks whilst ensuring the rights of an individual and to offer aid in times of crisis. This support can be domiciliary, within residential and nursing homes or other community settings. A fundamental difference to care in the NHS care is that most of these services involve an assessment of a person's eligibility in terms of need and financial resources (thus means-testing). The quality and sufficiency of these services has a far-reaching impact on the lives of the most vulnerable in society and reflects the values of contemporary society (Association of Directors of Adult Social Services (ADASS), 2018). The demand for services is increasing. The NAO (2016) has estimated that between the years 2010-11 to 2016-17, the numbers of those aged 65 years and over in need of social care in England increased by more than 14%, and those in need of social care aged 18 to 64 years increased by more than 9%. Furthermore, research during the last 10 years indicates that the care needs for those over age of 65 domiciled at home are not being met (Vlachantoni, 2019; Vlachantoni et al., 2011).

2.18 Transforming Health and Social Care

To promote these changes in care, policy initiatives and the political rhetoric advocated individualised care and personalisation as central tenets (Needham, 2011). In the Valuing People White Papers (Department of Health, 2001, 2009) ‘person centred planning’ was a central theme. The People First (Department of Health, 2007) concordat detailed a vision for the development of a ‘personalised’ adults social care system. As part of these developments a co-production model of care and support was advocated for the design of services. This approach is predicated on valuing and developing the assets and expertise of services users and carers (Department of Health, 2010b). Individuals and their carers are viewed as active participants in care, with reciprocity and mutuality between professionals. It was argued that it offers scope to alter how services are delivered or commissioned without increasing costs (Knapp, 2010; Stevens, 2010). However, others view this as a cost saving approach (Needham, 2011). Personalisation in its broadest sense is about how services are constructed and tailored to meet the needs of individuals and to improve outcomes for those using services (Larkin & Dickinson, 2011). Configuration should be from a service user perspective rather than established norms of delivery to ensure individual support and service user choice and control (Dickinson & Glasby, 2010). However, in re-designing services, the role of carers needs to be properly recognised and their views should be sought if the process is to be truly inclusive and empowering (Larkin & Dickinson, 2011; Larkin & Milne, 2014). The political and statutory focus on personalisation and the care market is clear. In the Care Act (2014) guidance, there is a continued emphasis on personalisation and care markets, and both are inextricably linked as follows: ‘High quality, personalised care and support can only be achieved where there is a vibrant, responsive market of service providers’ (Department of Health, 2014 para, 4.1)

Two particular levers have been utilised as a means of achieving personalisation through the introduction of direct payments (DPs) and personal budgets (PBs) (Needham, 2011). In the Care Act (2014) the eligibility for personal budgets for family carers was extended. For older people outcomes from the use of personal budgets for both service users and carers has been less favourable than those who are younger

with lifelong disabilities, with reports of lower psychological wellbeing compared with previously managed LA care and older people expressing caution about the budgets compared to younger disabled people (Glendinning et al., 2008). The uptake is lower in the elderly, although carers will accept this responsibility to improve the quality of care and support for the care-recipient. However, it has been found that they are often inadequately supported to take on such a role (Woolham et al., 2018). It has not been clear how PBs have been negotiated with the elderly and their carer(s), what their view may be on this approach and what may aid their uptake and use of PBs (Newbrunner et al., 2011; Moffat et al., 2012).

Following the Care Act (2014) the requirements to address carers' needs has also been strengthened, with parity of esteem between carers and care-recipients. Thus, the right to an independent carer assessment, a requirement for LAs to fund support to meet their eligible needs alongside providing information and advice is now enshrined in law. Given that the eligibility for an assessment has widened, arguably then more carers will be able to access an assessment. Pickard et al. (2016) have cautioned on the expectation that the new legislation will substantially alter those who present for an assessment. If the net is to be widened beyond the most vulnerable carers, and those giving the most intense caring, more resources will be needed. Reduced resource availability will hinder identification of those hidden or invisible carers thus further limiting support to carers. Findings that have assessed the impact on carer assessment since the Act came into force are disappointing. The NAO (2018b) figures estimate that 6 per cent of carers receive support from adult social services. Carers UK, (2019), have also reported that only 27% of carers had been assessed or reassessed in line with the Care Act and for the majority of the carers who had the assessment, they felt their needs were not given full consideration.

As services transformed in social care, parallel policy objectives in healthcare also promoted choice for users of the NHS with a much greater and equal role of patients/service users and their carers in determining treatment (Ham, 2014; Ham et al., 2012). This approach has also been based on the principles of co-production and has included a focus on patients/service users and their carers as experts in their understanding and knowledge of their illness and treatments (Greenhalgh, 2009; Wilson, 2001). As the prevalence of long-term conditions has increased, the emphasis

on self-management has been linked to the underlying discourse of choice, autonomy, and responsibility. Shared decision-making is central to this approach with an expectation that doctors, and other professionals will understand what patients/service users and their carers want and provide better information on treatment options, potential outcomes, and the supporting evidence for the care options (Mulley et al., 2012). It is argued that self-directed care enables patients/service users and carers to take more control over their prescribed care and the services and support they need. The Expert Patient Programme (EPP) alongside the increasing recognition of the carer role in relation to managing long term conditions and disability (Department of Health, 2010a; HM Government, 2008; NHS England, 2014a, 2014b, 2016) has altered the relationship between health professionals, care- recipients and carers. However, although this approach considers both as 'experts by experience' the reality is that this is not always the case when interacting with health and social care professionals (Aasbø et al., 2017; Allen, 2000; Shim, 2010; Wilson, 2001).

Previously the legacy of the medical model of care, with power residing with health professionals, led to an expectation that patients/service users and their carers would be compliant. Furthermore, professionals may still be viewed as the expert, not the patient (or carer) and they continue to have a gatekeeper function in their role in enabling access to services and care provision (Collyer et al., 2017; Crinson, 2008; Freidson, 1988; Wilson, 2001; Fotaki, 2010). However, there is a shift in professional attitudes associated with a recognition by professionals that many will not, comply with treatments if patients' beliefs and decisions are not considered and recognised (Taylor & Bury, 2007). Increasingly, through their individual and collective agency patients and carers are seeking sources of information and advice from the internet and through self-help groups. This offers a means of determining and controlling their care trajectory and treatment options (Abendroth et al., 2014; Greenhalgh, 2009; Jeffries et al. 2015; Morris et al., 2015; Vassilev et al., 2014). Although the shift in power-relations between carers/patients/service users and health professionals has been broadly viewed as a positive change, there is scepticism about the approaches that have been promoted (Taylor & Bury, 2007). The introduction of self-management programmes promotes a model of illness, based on changing health behaviours and is individualistic in its approach (Greenhalgh, 2009) thus ignoring the social context and

other determinants of health (Marmot, 2010) and can lead to victim blaming (Taylor & Bury 2007). Others argue that more holistic models that encompass the family, social, political, and economic contexts are needed (Greenhalgh, 2009). It should also be acknowledged that not all will want to accept responsibility. Furthermore, many may not have the intrinsic or extrinsic resources available, for the management of their long-term conditions (Allen, 2000; Greenhalgh, 2009; Wilson, 2001)

2.19 Consumerism, Choice and Control for Service Users and Carers

The reforms of the public sector from the late 1980s heralded an increasing wave of policy discourse in relation to consumerism, choice, and control (Appleby et al., 2003). These are reliant on active participation of those needing care and support and in designing and shaping the service (Appleby et al., 2003; Collyer et al., 2015). It is also reliant on the availability of a range of services of acceptable quality to choose from. This discourse of choice and control requires the state and its associated institutions to be responsive and effective in meeting the needs of its citizens (Glendinning; 2012; Appleby et al., 2003; Collyer et al., 2015; Collyer et al., 2017;Yeandle et al., 2012). Thus, as the reforms associated with community care progressed there was a transformation in how service users and carers were viewed in the discourse of politics and policy. The establishment of care markets and the shift in view from that of service users as passive recipients of care to one of active consumers also aligned with disability movement activists who had been critical of the paternalistic and rigid approaches to services. A highly organised carer movement has also gained momentum and support since the 1960s. The collective and individual voice of carers have aimed to exert effects on the policy direction and improve the outcomes for carers (Yeandle et al., 2012). Demands for parity of esteem with care-recipients and therefore proper carer recognition as enacted in the Care Act (2014) have formed part of this lobby. Yet despite greater recognition and rights, many carers remain invisible or hidden (Barnes, 2012; Cavaye, 2006) and receive little support from the state (NAO, 2018b; Carers UK, 2019; Hand et al., 2018). Thus, Larkin and Milne (2014) have argued that achieving greater carer empowerment requires a more detailed on-going

examination of the theoretical and conceptual approaches that can define and encompass the social, political, legal, economic, and ethical dimensions of care and caring.

In relation to a carers or care-recipient's choice of services and support, this can be determined by the care-giving relationship and by organisational factors that are beyond the carers' control (Arksey & Glendinning, 2007; Shim, 2010). Yeandle et al., (2012) argue that reconfiguration and pluralism of services extends the options available to agencies providing the services but not necessarily to those requiring those services. Furthermore, consumerism offers choice principally to those with the financial resources to 'top up' on the limited services available via publicly funded options (Yeandle et al., 2012). Other factors will also potentially impact on the equity of choice, particularly in relation to cultural health capital, education, social class and ability to travel to reach the services of choice (Fotaki, 2010; 2014; Appleby et al., 2003; Shim, 2010).

2.20 The Impact of Austerity and Increasing Demand on Health and Social Care Services

While undertaking this Doctorate, the health and social care systems have come under increasing pressure since the austerity measures that began in 2010. Spending on social care in England in real terms, (given adjustments for inflation), since the 2009-2010 period when it was at its highest has fallen. In the 2015-2016 financial period the money spent on social care was just under £17 billion and yet £17.2 billion (in real terms) was spent in 2005-2006, (ONS, 2017). Over time the cost of domiciled care has increased leading to more 'intensive' care packages. An intensification of need in client groups has been observed across the adult social care sector including the voluntary sector, domiciliary care as well as residential and nursing care. Key providers see this because of the agenda to keep people at home longer (Humphries et al., 2016).

Although funding for the NHS has largely been protected during the last 10 years the impact of an ageing population and a stretched social care sector has also been felt by the health service. Unsurprisingly older people account for 62% of all hospital bed days and the majority (52 %) of admissions that involve hospital stays of more than seven days (NAO, 2016). This has meant that both in-patient and out-patient services have found it difficult to provide the capacity to meet demand (Humphries, 2011). The Care Quality Commission (CQC, 2016) has found that although both sectors are committed to an integrated approach to care, actual delivery remains disjointed and lacks cohesion. It also found that poor connections between services resulted in older people and their informal carers having to navigate complex local services. Information for carers and service users about the co-ordination of their health and social care following a change in circumstance or if there was an unplanned or emergency admission to hospital was poor. This had the potential for an individual (and their carer) to fall in the gaps between services with identification only at times of crisis (CQC, 2016). Before austerity, the state was only able to meet a proportion of the care needs for the older population. Thus, increasingly for those who cannot rely on or obtain care, they must rely on their own resources including finances, and family and friends to support them (Baxter & Glendinning, 2015). As a consequence of this shift to community care, the involvement of the family and other informal carers as the main providers of care has become an integral requirement to address the needs of an ageing cohort in a time of severe fiscal constraint (Dow & McDonald, 2007; Glendinning, 2012; Humphries et al., 2016).

2.21 The Carer's Position at the Interface of Formal and Informal Support

Although, following the Care Act (2014) the requirements to address carers' needs has been strengthened, with parity of esteem between carers and care-recipients, there are competing policy discourses that carers must navigate in their role. Carers in their role find themselves positioned at the boundaries between their personal life,

their work, their community and the providers of health and social care. At these junctions, they must reconcile their role and the social and cultural expectations and demands of society. (Brossard & Carpentier, 2017; Egdell, 2012b; Pickard et al., 2016; Pickard, 2010).

2.21.1 The Blurring of Boundaries Between Informal and Formal Care

The 'mixed economy' of care with increased pluralistic models that include the state, the market, TSOs and the family (Evers, 1995) have led to a changing relationship between informal and formal care (Yeandle et al., 2012). Daly and Lewis (2000) argue that there are multiple intersections that occur in social care as it crosses public and private spheres in terms of the state and family, the state and market provision; formal and informal care; paid and unpaid care; and provision in the form of cash and services. Greater carer recognition, the right to be independently assessed, alongside financial support (primarily through carer allowance) and access to personal budgets in line with the personalisation agenda have altered the dynamics between the formal and informal sectors. This has seen the commodification of care as these policy changes have attached payment to caring activity, which previously was unpaid, and thus unpaid caring and paid care has become hybridized with a 'shifting and blurring' of the formal and informal care sectors (Ungerson, 2003; 2005, p. 189). Thus, a mixed workforce has evolved that operate with differing intensities and across potentially multiple locations. Structural aspects (power relations, gender and the gendered nature of care, formal care availability and funding) also impact on the interface between formal and informal care provision and are context dependent (Barnes, 2012; Cavaye, 2006; Finch & Mason, 1993; Groen-van de Ven et al., 2018; Jaglal et al., 2007; Kemp et al., 2013; Twigg & Atkin, 1994)

Carers and formal care providers will offer different perspectives of the role of the carer (Glendinning et al., 2014; Nolan, 2001; Twigg & Atkin, 1994). The interaction between informal and formal care and the role of the carer in this process have been described in several ways. Nolan et al (2001 p. 94) describes the carer in their interactions with those providing formal care as an 'informant', a therapy assistant and co-client, collaborator, and director. From a detailed analysis of the carer-service

provider/professional relationship Twigg and Atkin (1994, p.11) describe the 'ambiguous' position of the carer in relation to formal service provision. From this and building on earlier work (Twigg, 1989) they developed a typology of caring as follows:

- Carers as resources, viewed as a free resource separate to formal provision
- Carers as co-workers, working alongside formal service providers with a shared approach in delivering care and the well-being and importance of the carer recognised
- Carers as co-clients, who need to be supported with services directed to aid them
- Superseded carers, where the carer-recipient is no longer dependent on the carer

The prevailing socio-political economic and cultural contexts (Carpentier & Grenier, 2012; Egdell et al., 2010; Pickard, 2010) all impact on these interactions. An emphasis on carer recognition and the need to improve how formal services work in partnership and collaboratively with the carer has also become more prominent in policy directives (Department of Health and Social Care, 2018a; NICE, 2020). It is argued that there is an illusion of choice in terms of service provision for carers and care-recipients since 'exercising choice are circumscribed by factors outside their control' (Arksey & Glendinning, 2007, p. 169). Factors such as increasing financial constraints; restricting eligibility; reducing services; and the increasing difficulties encountered with the availability and suitability of formal paid care staff to provide the care required, all impact on the carers' role and their interaction with the formal care sector. Local authority (LA) services and TSOs that have offered key support to carers have seen funding cuts. These are detrimental to the care-recipient and creates pressure and demand on the NHS as local social services fail to deliver support (Barnes, 2012; Carers UK, 2016a, 2019; Humphries, 2011; Humphries et al., 2016; Oliver et al., 2014). Thus, despite greater collaboration and co-production in the design and delivery of services with carers and care-recipients the tensions in relationships between formal and informal care as highlighted by Twigg (1989) over 30 years ago still exist. Drawing on personal narratives, Pickard (2010) has highlighted the paradox and heterogeneity of modern discourse for older carers in their role. As they negotiate their role at the interface of the formal and informal sectors, the decisions and actions

of carers are shaped by the social context that the carers find themselves in and by the discourses that they are subjected to. Thus, they balance the more traditional discourse as reflected in health and social policy with an expectation of care from the family alongside the competing liberal discourse that relates to choice and autonomy for individuals within society. Pickard (2010) found that based on their personal, social, and economic capital, carers will utilise and interpret such discourse to determine their definition and understanding of the role and shape their own moral choices in performing that role.

2.21.2 Exploring the Informal and Formal Care Interface: Links and Relationships

Despite the recognition of the interdependence between the formal and informal care networks there has been little research that has examined how through social processes relationships and links between providers of services and those who use them are made (Carpentier & Grenier, 2012). For those with long term care needs, the relationship between the formal providers, the care recipient and informal carer can be a long one. Therefore, understanding the complex interactions between health and social care professionals, unqualified care workers, and informal carers within the wider informal networks and care context is important. Such understanding can enable the development of stronger partnerships in providing care, ensuring that services reflect and meet the need of service users and their carers. In this study, a social network approach will be used to closely examine the networks that surround the carer in their role and how the links between those in the network support them in their role.

2.22 Part 1 Summary

This broad critique of the literature has examined the context and challenges of care for those with PD. The social and relational dimensions of care alongside the importance of the social networks of older people and the resources and support that these might offer have also been explored. The concept of social capital through bonding, bridging, and linking social capital offers a lens to consider how these

resources might be located and utilised for the caring role. Discussion of the carers and care-recipient's position within the informal and formal care networks has illustrated the complexities of each and how the boundaries between these have become blurred. Socio-demographic changes mean that the availability of kin to care for the growing numbers of elderly in society is precarious with a predicted shortfall of informal carers over the next decade. Austerity measures and the evolving policy context over the last 30 years has also resulted in significant changes to health and social care delivery with an emphasis on community care and an increasing reliance on informal care provision. As part of this, TSO's now also have an important intermediary role. Consumer choice and control, with greater responsibility expected of those with a long-term condition to actively manage their health have formed part of the altered rhetoric. The design and delivery of services is based on co-production and personalisation and legislation has placed carers in esteem with service users with a right to an assessment and support if needed. However, despite these changes, carers, who are in a pivotal position at the interface of the informal and formal, sectors still feel undervalued and unrecognised with few obtaining the resources they need to support them in their role.

2.23 Part 2: The Networks of Informal and Formal Care: A Systematised Review

This chapter will now continue and provide a detailed systematised review of the literature in relation to the empirical work that has examined the social/care networks and inherent social capital of carers and care-recipients over the last 20 years. This considers the characteristics of the networks, their function, resources, and the associated social processes inherent within. Empirical work that has explored the position and role of community and formal care provision in relation to carers' and care-recipients' networks will also be examined. Thus, data on the phenomena that arise at the interface of the informal and formal care sectors will be presented. To identify, evaluate and interpret the relevant research in relation to the study a critical examination of the available evidence available was undertaken (Grant & Booth,

2009). This systematised review enabled an objective and robust approach to evaluating the literature (Smith & Noble, 2016).

The systematised review process supported the following:

- Summarising of the evidence to develop and refine the research question(s)
- A critical appraisal of the literature to understand any methodological limitations
- Identifying existing and emerging themes
- A means of identifying gaps in the current research and possible areas for further investigation.

2.23.1 The Review

A search strategy was planned with inclusion and exclusion criteria, identified terms and key words to be used and the selection of the appropriate databases.

Inclusion criteria for the review were as follows:

- Studies published since 2000. This allowed for a search that would be comprehensive and would reflect the increasing focus on care and carer related issues since the start of the millennium
- Studies available in the English language. Resources were not available for translation of papers not published in English
- Studies that examined care networks and included data obtained from care recipients and/or informal carers
- Studies that examined care networks and included formal/volunteer carer data if there was data also included from care recipients and/or informal carers
- Studies including informal carers aged over 18 years of age. For this study adult carers were the focus hence this criterion and given the issues pertaining to child carers are different in many aspects
- Studies principally focused on the care of older adults and/or those with Parkinson's Disease, a long-term condition or life-limiting condition. Although there is literature on those who care for somebody with PD, this is limited and therefore expanding the type of conditions enabled a wider understanding of the available evidence
- Studies based in North America, Europe, Australia, and New Zealand

The exclusion criteria were:

- Studies where the only participants were carers delivering care as an employee in either a paid capacity or as a volunteer via a recognised agency
- Studies focussed on the care of children
- Studies only focussed on cancer or end of life care
- Studies outside of North America, Europe, Australia, and New Zealand

The review searched for resources meeting the above inclusion criteria. The following terms were used in the search which were identified based on the research questions and *a priori* grounds. These included the following terms and key words in the title or abstract which were searched using Boolean operators in a range of combinations: (carer OR caregiver OR caregiving OR older carer) AND (network or social network OR social capital OR social support). To then refine the search to the carers of those with Parkinson's Disease the following term was also added Parkinson*. This approach was supplemented with further searches of the reference lists of relevant articles and key journals. The Carer Research and Knowledge Exchange Network was also regularly accessed. This is a large database of literature and evidence on care and caring housed with the Open University in the UK. Grey literature and associated websites such as Carers UK and Parkinson's UK were also part of the search. The search criteria generated a wide range of literature and citations. EndNote™ enabled management of the search data and allowed identification of any duplications. Searches were undertaken from September 2012 until September 2020. Utilising the following electronic bibliographic databases allowed for a comprehensive search that covered the social sciences, medicine, nursing, and allied health disciplines.

- BNI
- CINAHL Plus
- MEDLINE
- SCOPUS
- TRIP
- Web of Science

A PRISMA style diagram has been included to demonstrate the process (see Appendix 1). A table of those studies that have been included is also available (see Appendix 2). Information was extracted from the studies using the following: author(s), year of publication, country of origin, journal, article title, study aim and objectives, research question, study design, sampling method, sample information, sample size, data collection method, data analysis, key results, and study limitations. Each of the studies were assessed using the Critical Appraisal Skills Programme (CASP) (2018), cohort study and qualitative checklists.

2.23.2 A Summary of the Included Studies

A total of 38 studies (see Appendix 2) that met the inclusion criteria are included in the review. Five studies were based in the UK (Egdell, 2012a; Egdell, 2012b; Egdell et al., 2010; Katbamna et al., 2004; Rutherford et al., 2014) and the rest were internationally based as follows: Australia, 2; Belgium, 1; US, 9; Netherlands, 6; Canada, 11; Spain, 1; Republic of Ireland, 1; Denmark, 1; Finland, 1. The studies selected principally collected data directly from carers or through datasets that held data specifically on carers (20 of the published papers). However, several studies not only collected data from carers but also care recipients and in some cases the wider circle of informal carers and/or professional and voluntary carers who were involved in the overall delivery of care. Three studies had data on non-kin informal carers (Fast et al., 2004; Jacobs et al., 2018; Lapierre & Keating, 2013). Within some of the studies included in this review (Broese van Groenou et al., 2016; Fast et al., 2004; Jacobs et al., 2018; Jacobs et al., 2016; Jansen et al., 2019), the focus has been on the wider care network rather than just on the primary carer and immediate kin. This offered a wide-ranging picture of the informal and formal networks from multiple perspectives. The primary carer is integral to the network of care and an understanding of the wider contribution that others may be making to the provision of care may help to identify those who support and assist the carer in their role which aligns to the aims of this Doctoral study.

The inclusion criteria for this review included the care of older adults or those with a specified long-term condition or disease. Only one study was found that specifically addressed the networks of carers of those with PD (Abendroth et al., 2014). Another study specifically focussed on examining the social support networks of carers of those

with Motor Neurone Disease (Ray & Street, 2005). Other studies, included as part of this review, included carers of those with a diagnosis of dementia or Alzheimer's disease. More generally care-recipients were stated as being aging or frail with the majority of the care recipients being over 50 years old. In a UK based study, Katbamna et al. (2004) specifically addressed South Asian carers and the nature of informal support that was available to them in nuclear and extended families. Although the care-recipients associated with this study were of all ages and had a variety of illness/disabilities the study was included because of the unique insight into the networks of this ethnic group. Two studies in the review examined the social capital associated with the carers network (Keating & Dosman, 2009; Roth, 2020). Studies were wide ranging in their methodological approaches. Predominantly the studies were qualitative. However, 12 were quantitative with data taken from planned or existing surveys and six used a mixed methodology.

2.24 Themes Identified from the Review

In analysing and critiquing the evidence the significant themes that were aligned with this study are as follows:

- Parkinson's Disease and carer peer support
- Characteristics and typologies of the care networks
- Primary carers
- Network dynamics
- The interface between informal, community and formal care

The following sections will present a critique of the research in relation to each theme.

2.25 Parkinson's Disease and Carer Peer Support

The only study identified that examined the networks of carers of those with PD was based in the US. This examined the views and experiences of 20 carers of those with PD who were part of a peer-led support group (Abendroth et al., 2014). Semi-

structured interviews were analysed using grounded theory to categorise the carers' experiences. Although it was noted that the networks described had many informal and formal types of support (these were not clearly elaborated in the findings), the findings presented concentrated on the value that the carers placed on their involvement in the peer-led support groups. From this aspect four themes were described as follows: 1. Illness uncertainty, where carers valued sharing their experiences of the unpredictable nature of PD, in a safe environment and with those who understood the illness. 2. Broken connections; in this aspect the course of the illness led to difficulties and loss of relationships with friends, family, and health care providers. However, sharing experiences with others gave the carers validation and helped them deal with these losses. 3. Intimate connections; for this theme developing close relationships in the groups built on trust and opportunities to share and disclose their experiences was valued, and 4. Lifeline to other carers, which represented how carers wanted to support others outside the group and ways in which the carers might aid them through respite, information, empathy, and support. Thus, it was evident that peer-led support was clearly valued and an 'oasis' (p.51) for PD caregivers. Although this study was small and based in the US it offers a valuable perspective on PD support through organisations that are separate to the formal networks of support via health and social care.

2.26 Characteristics and Typologies of the Care Networks

Examining the characteristics of care networks allows an understanding of the various ways that the different members within the network operate together to provide care. The composition of the care networks was described or outlined in these studies (Fast et al., 2004; Feld et al., 2006; Sims-Gould & Martin-Matthews, 2007) and a typology of care networks has been delineated by Broese van Groenou et al. (2016); Jacobs et al. (2018); Keating and Dosman (2009); and Rutherford et al. (2014). Other studies have focussed on how gender (Rodríguez-Madrid et al., 2018; Sanders, 2007), age of the carer (Ray & Street, 2005) and ethnicity (Feld et al., 2004; Katbamna et al., 2004) also influence the characteristics of the care network.

In a large cross-sectional study (n =1104) on data from the Statistics Canada General Social Survey, Fast et al., (2004) examined data from care-recipients on those providing care to them during the previous year. The data was collected on those aged over 65 years who had received assistance from at least one family member, neighbour, or friend (on a specified set of tasks, including meal preparation or cleaning up, housework, shopping, transport, home maintenance, banking/bill paying, personal and/or emotional care and general checking of welfare). How often the task was performed by the carer and the time spent on each occasion was noted. The variables (size, gender, age and relationship composition, and proximity) were found to be highly variable in the care networks. In line with previous work (Wenger, 1997), many of the networks were found to be small, female dominated and mainly composed of kin. For many care-recipients the network comprised of a solitary female. The analysis of the network characteristics helped to explain the types and the amounts of care received. Networks that might place the care-recipient at risk of not receiving adequate care were found to be small networks, with higher proportions of non-kin, male and geographically distant network members.

2.26.1 The Informal Network: Care Beyond the Dyad

When examining care networks an important consideration is the range and number of those within the network either providing support directly to the care-recipient or to the primary carer. The following studies by Feld et al., (2006) and Sims Gould and Martin Matthews (2007) have examined care beyond the primary carer. In the study by Feld et al. (2006) previously collected data from a national study, the Asset and Health Dynamics among the Oldest Old (AHEAD) was examined. The study aimed to understand the role of the spouse in caregiving in the context of factors that might influence how the care network might expand beyond the spouse as the primary carer. This was a US study based on a representative sample of older Americans (70 years plus). Data from both Black and White couples (n=427) where one partner required support for instrumental activities of daily living (IADL) was statistically analysed to assess how the care network was expanded in response to the need for instrumental support. Where the partner as carer had IADL/ or activities of daily living (ADL) limitations themselves and the care-recipient was a wife or had numerous IADL/ADL

difficulties, expanded networks were significantly more likely.

In examining the wider network beyond the carer-care recipient dyad, Sims-Gould and Martin-Matthews (2007) verified an adapted version of Kahn and Antonucci's (1981) model and Cantor's (1991) social care model. This adapted model, considered direct support to the care recipient and support between carers and helpers. Data was taken from the Work and Eldercare Research group of CARNET (the Canadian Aging Research Network). As indicated in both the Fast et al. (2004) and Feld et al. (2006) studies, this too demonstrated that primary carers do not act in isolation from the surrounding family with carers often receiving help in their caregiving. Many different individuals may give direct care such as spouses, sisters, sisters-in-law, brothers, and brothers-in-law. These may also give assistive help as do other family, and friends. Thus, family caring can involve multiple individuals aiding one another alongside giving direct care to the ageing relative or friend. Statistical analyses illustrated the type of help provided and were useful in emphasizing the interconnections between direct help and the activities of the respondent carer. Unsurprisingly, the types of care provided by helpers was significantly related to the care provided by the main carer for a range of types of care (including general household and emotional activities). Spouses were the number one direct helper for non-primary carers while sisters were the number one direct helper for primary carers.

2.26.2 Care Network Typologies

In developing a typology of network types from the findings, a deeper insight into the core composition of the networks is possible. The variables that influence the different typologies alongside other factors that may impact on how the care network operates are also elucidated. In each of the following studies, Keating and Dosman, (2009); Jacobs et al., (2018); and Rutherford et al. (2014) used large data sets held in public/national databases to identify care network typologies. In a mixed methodology study, Rutherford et al., (2014) also used qualitative interviews with carers and care-recipients to verify the typologies that emerged from the network data and to gain a more detailed understanding of the network structure. Broese et al., (2016) recruited a smaller number (n= 74) care recipients via home care organisations

In Table 4 the typologies from each study are listed with details of the databases that were used, alongside the participants and the care-recipient characteristics. Jacobs et al., (2018) and Broese et al., (2016) clearly identify the informal/formal networks within their typologies whereas Keating and Dosman (2009) and Rutherford et al., (2014) are based on the informal care networks but in their findings, they acknowledge the involvement of formal care (privately and/or publicly paid for). Interestingly, Keating and Dosman (2009) also consider the social capital associated with each typology. Using a social capital framework, the types of care networks supporting older adults and how they might differ in their structural characteristics and the differential potential of these networks to provide care and to access more formal care support were examined. Respondents indicated that they had received care from family/friends in the previous year due to a long-term health issue or disability. Care was defined as previously stated in the Fast et al. (2004) study. The networks identified all family members and friends that the respondent listed, and formal care was determined as care from Non-Governmental Organizations (NGOs), privately paid employees or those employed by a government agency.

The network characteristics including gender and age composition (proportion between 45 and 64 years versus proportion of those over 65); relationship (kin versus non-kin); geographical proximity (those living with the care recipient compared to those more than a half day's travel away from the care recipient); employment (proportion employed full or part time); and network size (number of members in the care network). A typology of six care networks were derived from this (see Table 4). Three of the networks (lone spouse, children at home and spouse and children) were predominantly family based whereas the other based networks were a diverse group that included both friends and family.

Table 4: Typologies of Care Networks

Study Authors Country	Data Source and Key Participants and Care Recipient Characteristics	Care Network Typologies
Keating and Dosman (2009) Canada	Statistics Canada, 2002 General Social Survey on Aging and Social Support Key participants; care recipients (n = 2,407) Care recipient age >65 years receiving specified care/assistance	Lone spouse Children at home Spouse and children Close kin and friends Older diverse Younger diverse
Rutherford et al., (2014) UK	British Household Panel Survey (BHPS) 2006 Key participants, carers, and care recipients. Care recipient age >50 years (n=5429). Interviews, care-recipients age >65 years plus carers (field work data, disability and condition not stated)	Care from spouse within household Care from child(ren) outside the household: (a) while living alone (b) while living with others Care from children living within the household Other living arrangements- (e.g., living with a sibling or friend) and receiving informal care from extended family
Jacobs et al., (2018) Netherlands	Longitudinal Aging Study Amsterdam (LASA) 2011-2012 Key participants, care recipients Care recipient age >65 years (n=491) (receiving care from at least 2 types of carer, paid, informal or volunteer)	Privately paid Coresidential Large informal Publicly paid
Broese et al. (2016)	Data from contacts via home care organisations. Key participants, care recipient, informal and formal carers Care recipient age >65 years (n=74) (receiving care from at least 2 types of carer, paid, informal or volunteer), informal carers (n=94), formal carers (n=102)	A small mixed care network A small formal network A large mixed network A large formal network.

The second series of analyses examined the structure of the networks and the influence on actualized social capital i.e., the amount of care provided by the networks, and by formal care services. Two groups were apparent, and these were care-recipients who received family/friend care only and care recipients who received family/friend and formal care. The distribution of hours of care within each of these two groups was further examined for the six care network types. There were similarities across the networks in the hours of care provided when formal care was absent or received. Although the mean hours of care were similar across four of the care networks, when informal networks were sole providers of care, in the younger diverse networks there was less care, while in the spouse and children networks there was more. For those networks which included formal services, the mean hours received in formal services varied little across all six network types. However, when formal care was also provided, close-family networks provided substantially more care per week compared to friend-and-family networks. It was surmised that close-family networks may be reluctant to link to formal services and when they do, they are at the limit of their caring resources, whereas lower care obligations in mixed friend and family networks may limit the care provided once formal services are involved. Thus, family care was found to be central and represent the concept of bonding social capital. Spouses and adult children appeared to have high normative obligations to provide care and there was evidence of a strong commitment as evidenced in the hours of care provided even when formal care was also involved. Each network had some close-kin, and thus bonding social capital appeared a pre-requisite to the care network. The authors argued that the more diverse networks with the presence of friends and more distant kin allowed for bridging social capital to access community resources. Thus, in the diverse networks they were more likely to receive formal services than were close-family networks.

In the UK based study, Rutherford et al., (2014) used a mixed methodology to examine the care networks of older adults. In a sequential design, quantitative survey data followed by qualitative interview data from older people and their informal carers was obtained. The data was used to ascertain the care relationship between two individuals alongside the directionality of that relationship (one way or reciprocal). Formal care links were illuminated from data on the household access of home help, meals, social work support, physiotherapy, and hospital visits. To add to the detail of the emerging

typology of the networks a purposive sample of older carers and care recipients from 25 households were interviewed. This allowed a more in-depth understanding of the factors involved in the formation and development of the networks and the decision making associated with the networks. The typologies in this study are also presented in Table 4. The qualitative aspect of the study gave a greater insight in to the factors affecting decision making in terms of care preferences and arrangements. Analysis of the interviews also demonstrated ‘the importance of timing and path dependency’ (p.485) that leads to the composition and form of the network as observed.

In a European study Jacobs et al. (2018) focused on the diversity found in care networks in the Netherlands with the formal networks of care also included in this typology. For the purposes of this research, the complete data collected from those receiving at least one of five types of care each day was analysed. Respondents were asked to indicate if they received assistance with the following: IADLS and ADLs; Nursing; Transport and administrative tasks and who provided the care (e.g., partner, paid caregiver) for each task alongside the frequency and number of hours of care provided. The typologies were formulated (see Table 4) from latent class analyses that identified homogeneous subgroups with similar care networks. In the privately paid network, most help was financed by the care recipient and few other carers were present. Household care was the main support received. The coresidential network consisted of partners mainly or other co-resident carers and although in some cases there was privately paid help the majority were comprised of informal carers. A significant number of these cases had one lone carer which were mostly partners of the older adult care recipient. The care recipients in large informal care networks received support from non-resident children, other family, and neighbours. For some publicly paid and/or privately paid help was also present. The care recipients in the final category all received publicly paid care, although informal care was also present. A relatively large number of formal carers were involved, and the care recipient received help with a range of tasks including personal and nursing care. Of those with partners, only a quarter provided help to their partner.

The final typology presented by Broese et al., (2016) also identifies care from both informal and formal carers in a ‘mixed care network’ (p.95). A particular feature of this

typology is the elucidation of the linkages between the informal and formal care networks of the care-recipients. Structure and functional features (including contact and the nature of the tasks undertaken by each) was examined to understand the contribution of the formal and informal carers in these mixed care networks. Care recipients living at home, who were receiving care from both informal and formal provision were included and a selection of their informal and formal carers interviewed. The data collection detailed the contact between the paid/unpaid carers and was found in 34% of the formal–informal dyads. It was also found that both carers performed at least one similar type of task in 29% of the dyads. Examining the size, composition, contact, and task overlap gave rise to the identification of four network types (see Table 4). Further bivariate analyses between these four network types found that the recipients' functioning, memory, social network, their perceived control of care and level of mastery were significantly different. These results suggest that when considering network types from the formal-informal interaction, formal agencies may need to work differently dependent on the network typology. This might include mobilizing the smaller networks, considering task differentiation and the co-ordination of the larger care networks.

The significance of the spouse and adult children is recognised within all of these networks. Geographical factors in terms of residential status of the carers and care-recipients and the potential for networks that are more diverse, with members involved outside the family are also evident. Finally, inclusion of the formal networks in two of the studies enables a closer examination of the impact of this involvement on the network structure.

2.26.3 Gender and Network Differences

Two studies examined the informal networks of carers from a gender perspective, (Rodríguez-Madrid et al., 2018; Sanders, 2007). Rodríguez- Madrid et al., (2018) utilised social network analysis to determine the composition, structure, and function of 25 female and 25 male carers' networks. This analysis demonstrated differences (although not significantly different) between men and women in the network composition (gender, age, and place of residence) and function (emotional support). Women were predominant in both networks, but women received help mainly from other women with a similar demography to themselves. They also received less

support from people living nearby. However, male networks were more diverse and wider ranging with more help provided beyond the family including colleagues and paid formal support. A limitation of the study was the small size of the sample which may have affected the power of the statistical analysis in terms of determining significant differences. In a small phenomenological study (20 male carers) Sanders (2007) focused on the networks of male carers caring for an older adult with a chronic health condition. From this study the findings described how the male carers viewed the willingness of the informal support networks to help as follows; not involved with care; emergency assistance only; feel free to call if we could be of help and part of the caregiving team. Three further themes related to the willingness of the male caregiver to ask for informal support were discussed as follows; asked for assistance; felt guilty about asking for help and did not ask for help. This study demonstrated that some of the male carers had very good relationships with their informal networks and felt it was acceptable to ask for help. However, many felt isolated and did not find it easy to ask for support or did not acknowledge the support that may be available. Although the previous study (Rodriguez- Madrid et al., 2018) appeared to demonstrate greater diversity in male carers' networks, Sanders (2007) highlighted that men may have difficulties in asking for assistance.

2.26.4 Age of the Carer and Availability of Network Support

In an Australian mixed methodology network study using eco-mapping, observation and interviews, Ray and Street (2005) collected data from carers of those with Motor Neurone Disease (MND). The structure of the support network and type and strength of the relationships within the network were mapped and changes over time depicted on the eco-maps. The study examined the size and composition of the networks but the principal feature that acted as a discriminator for availability and consistency of support was found to be age. For carers in older age groups (>60 years of age) there were more diverse but consistent support systems whereas carers in younger age groups (<60 years of age) reported more variations in the strength of relationships with a reduction in support as caring demands increased. This suggested that assessment of the availability of support networks at regular intervals through the course of caring is needed. It also suggested that younger carers may need specific help to manage the psychological dimensions of care and access to formal paid care. For older carers

support with the instrumental demands of care and help in mobilizing their support networks may be needed.

2.26.5 Ethnicity of the Carer and Availability of Network Support

In a study based in the US the care network differences among older White, Black, and Mexican American (n = 531 married, n = 800 unmarried) were analysed (Feld et al., 2004). Ethnicity did not have an influence on the acceptance of IADL carers from outside the married partnership (for Black and White couples), when other factors were considered. There were no ethnic differences in the spouse being the sole provider of IADL or ADL care giving and the role of the spouse as carer was similar for both older Black and White care recipients. However, where a Black care-recipient had solely informal networks, they were significantly more likely than White older people to have informal helpers other than the spouse rather than rely solely on their spouses. In the UK qualitative study focused on ethnicity, Katbamna et al., (2004) assessed the quality and quantity of informal support available to male and female carers (n=105) of South Asian ethnicity. The care-recipients in this study were heterogeneous including all ages and had a range of physical and/or mental illnesses. Qualitative analysis indicated that both male and female carers had limited support in nuclear and extended family settings. Carers in nuclear and female-headed households appeared isolated and found it difficult to provide care without the practical and emotional support needed. Accepting and asking for help from the wider social network was hindered by normative attitudes towards disability and a fear of obligation on the carers part. The study therefore concluded that support cannot always be guaranteed from extended families.

In summarising the characteristics and composition of the care networks it is evident that the family (principally spouses and adult children) continue to be a lynchpin for care provision. By examining the intersection of the carers' age, ethnicity, and gender it is possible to elaborate how these features effect the network composition, and function providing more nuanced detail and recognition of the myriad of factors that might shape the network. Where longitudinal research has been carried out there is evidence of network change overtime. Longitudinal approaches are valuable in capturing structural changes and transitions in care networks over the caring trajectory.

2.27 Primary Carers and Network Support

Five studies have particularly examined the role and experiences of those identified as the primary carer in terms of the overall support from the care network (Dam et al., 2018); Sims Gould and Martin-Matthews, 2008; Szinovacz and Davey, 2007; Tolkacheva et al, 2011; Lapierre and Keating, 2013).

2.27.1 Spousal Carers and Network Support

A small qualitative study (n=17) by Dam et al., (2018) examined the perceptions, needs and experiences of spousal carers looking after a partner with dementia. Insights were also gained from some of those in the network who assisted in care provision. Semi-structured interviews utilising an ecogram and network card allowed mapping of those in the network and their function. Affective dimensions of the carers' thoughts on the availability of support and their experiences were also addressed. Most of the carers and their identified support in this study were female. Both barriers and facilitators to spousal carers asking for support were found (as were barriers and facilitators to offering support to the spousal carer). It was concluded that the spousal carers had different support needs including emotional, practical and respite support, with relaxation and companionship also identified. Although those in the network appeared to want to support the carer often no support was provided and therefore a discrepancy between the supply of and demand for support was evident.

2.27.2 Adult Children as Primary Carers and Network Support

The role of adult children as primary carers, the nature of their care network and their experiences were the of the following studies (Sims-Gould & Martin-Matthews, 2008; Szinovacz & Davey, 2007; Tolkacheva et al., 2011). Sims Gould and Martin-Matthews (2008) used response data collected from the adult child carers who answered open ended questions in the CARNET survey (this formed part of the larger cohort study described earlier in section 2.26.1 (Sims-Gould and Martin-Matthews, 2007). In answering questions on factors that helped them balance their work and family life and

what could make a difference to them in their caring role several themes were evident; the presence and importance of absent carers; the presence of multiple care recipients; the participation of men in helping and care giving; the balance of direct and assistive help, and the presence of paid helpers in care-giving networks. Responses from the carers regarding those who are absent or do not contribute did lead to frustration and a sense of inequity within the family dynamics. Although men were not as frequent in the overall network, they did provide care to their parents and parents in law and assisted other carers. Within the study many of these adult children were carers to more than one ageing relative and 30 % of the respondents indicated that paid help was vital to their experience of providing care. This suggests that informal and formal care can be viewed as a real partnership between the family and those being paid to provide care. Tolkacheva et al. (2011) in their study also utilised cohort data, taken from the Informal Care by Statistics Netherlands and The Netherlands Institute for Social Research on adult- child informal carers (479 women and 123 men aged 21–78 years). A path model demonstrated the impact of the network characteristics on carer burden, which was lower in the adult-child carer when the informal care network size was larger. It was also reduced when tasks were shared across the network over longer periods of time and when there was no conflict within the network.

In a longitudinal design utilising a large existing cohort dataset (waves one through to 5 of the Health and Retirement Study) Szinovacz and Davey (2007) analysed the changes in adult-child carer networks over two consecutive time-points. Fifty per-cent of all the adult-child care networks and 25% of the primary adult- child carers changed between waves. When examined gender and the availability of other adult children were particularly associated with change, although socio-economic factors, the abilities and resources of the carers, and carer burden also contributed to such changes. Considered from a life-course perspective, the observation was made that this has implications for future cohorts/generations where families are smaller with consequently fewer siblings available to share the caring responsibilities. In each of these studies the findings underline the importance of adult-child carers and the dynamic nature of family caregiving across the life course. Co-ordination of, and conflict within the network, needs also to be recognised by health and social care

providers when considering the capacity and resilience of the care network to continue to provide care.

2.27.3 Friends/Neighbours and Network Support

Within the carer literature the significance of non-kin carers i.e., friends and neighbours as primary carers and their involvement in the care network of adults with long term conditions has not been especially recognised. The General Social Survey of Canada data allowed comparison of individual and relationship characteristics, care tasks and amount of care provided vis-a-vis friends and neighbours (Lapierre & Keating, 2013). Factors such as interpersonal and socio-demographic characteristics were also analysed in terms of potential differences between the two in the patterns of care observed. Friends and neighbours differed by age, marital status, geographical proximity, and relationship closeness. Friends did a greater number of tasks, provided more hours of care/week and were more likely to assist with personal care, bills and banking, and transportation. Neighbours however were more likely to assist with home maintenance. This study illuminated the wider care network and further highlights the dynamics nature of the care network. It also raises the potential significance of friends and neighbours within care networks.

2.28 Network Dynamics

The dynamic interactions within the informal network have been examined from a wider family perspective (Jansen et al., 2019) and focussing on adult-sibling relationships (Leinonen, 2011; Amaro, 2017). The value of longitudinal design in assessing the impact of diagnosis on the network structure (Brossard and Carpentier, 2017) and the temporal effects on network structure and social capital have also helped to uncover network transitions (Roth, 2018;2020). Considering routes to network support from an economic, social, and cultural context also demonstrated the dynamic nature of care network formation and change (Egdell, 2012a; Egdell, 2012b; Egdell et al., 2010).

2.28.1 Family Dynamics in the Care Network

The dynamics of the 'informal care group' (p.375) were investigated by Jansen et al. (2019) in a mixed methodology design. The study aimed to determine the characteristics of the group, the obstacles they experienced, their needs and wishes and how GPs and other professionals might support them. A questionnaire was used (137 carers responded) and carers from nine informal care groups were also interviewed to obtain complementary data obtained in the survey. Overall family size was positively associated with the informal care group numbers and capacity. As found by Tolkacheva et al., (2011) the perceived burden of the individual carer decreased with increasing numbers in the network. The findings were positive in that there were few problems with clear communication, cooperation, flexibility in task performance, and agreements occurring spontaneously. Geographical proximity determined how tasks were shared, although household tasks tended to be undertaken by one carer. However, the positive relationships and interactions that were encountered in this study were not as evident in the following studies that examined the dynamics of adult children and their siblings in relation to the care of their ageing parents.

In a study based in Finland, Leinonen (2011) interviewed 20 (n= 18 females) working Finnish carers of a parent(s) regarding their relationships with their sibling and the sharing of responsibilities for their parents' care. The participation (or not) of their siblings in care was examined with most of the primary carers feeling that care was un-equal, although they did not try to persuade their brothers or sisters to participate more in care. Mainly siblings were absent or gave occasional support. However, for some there was shared care. The themes identified from the data showed that there were three patterns of participation, 'absence', 'backup' and 'togetherness' (p308). The reasons for the unequal division of care were discussed. The rationales for lack of participation of the absent/backup sibling included work-and commitments to their own children and grandchildren. However, relational dimensions were also evident that were subject to wider family dynamics, were path dependent in terms of a life course perspective and based on the relationship between the siblings or the relationship between the adult children and their parent(s). Work by Amaro (2017) also highlighted the importance of gratitude between siblings to maintain an equilibrium when providing care to ageing parents. Using a dyadic data collection, 54 matched sibling pairs (the

main carer and the main carers' adult sibling) were recruited. The data (amount of care provided, care conflict, trait gratitude, expression of gratitude and the burden of the main carer) was analysed using multi-level modelling. This indicated that dimensions of gratitude were related to reduced carer burden, aided care-related conflict, and promoted a greater contribution to caregiving.

2.28.2 Developing Care Networks, Social Capital, and Accessing Resources

The changes that occur in the care network over time have been examined in longitudinal studies (Brossard & Carpentier, 2017; Roth, 2018, 2020). Brossard and Carpentier (2017) using both a narrative approach and network data from 60 carers were examined in relation to action sequences using coding developed in previous work (see Carpentier, Pomey et al., 2008). The role of different alters in the network were identified and the events around the onset of symptoms to diagnosis were studied (Brossard & Carpentier, 2017). The team examined how diagnosis affected the care network. For 29 cases, there was no change, for 14 cases, it triggered network mobilisation, whereas for a slightly smaller group, diagnosis followed network mobilisation (13 cases), and for a minority, (4 cases) mobilisation was prevented. Thus, there was an 'intertwining' (p574) between diagnosis and those alters in the patient's network and the timing of the care network mobilisation.

To examine carers' networks particularly in terms of temporal change and the associated social capital within the networks at different time points, Roth (2018, 2020) used longitudinal data in the core discussion network module from two waves of the National Social Life, Health, and Aging Project (NSHAP). Data was taken from 1,360 carers with their stage in the role also determined (transition, enactment, and disengagement). In Roth's (2018) study, identifying the carers contacts at both waves meant it was possible to compare the turnover of carers' networks as they transitioned into the role with those of non-carers. As carers transitioned into the role, they added more contacts at higher rates than non-carers. Those who were carers during both waves and were disengaging from the role had no significant levels of network turnover. In the second study Roth (2020) utilised the concept of social capital as a theoretical approach and applied social network techniques to identify changes in the network structure over time. Using the potential for carers to exhibit bridging or

bonding social capital compared to non- carers was assessed and the changes in the social capital potential during the caring process (across the two waves) were compared.

The social capital potential of each respondent allowed comparison of the ties/alters associated with the carers and non-carers (ties were deemed as a bridging tie, if it was reported that the network member never spoke with any other network member or spoke with them less than once a year, whereas respondents were categorised as having bonding potential if they reported no bridging ties, defined as every network member being connected to at least one other member). Descriptive statistics and multi-variate analysis were used to illustrate the changes in social capital potential in carers and non-carers. Controlling for key characteristics i.e., sociodemographic variables, health and baseline network characteristics, the findings suggested that older adults transitioning into the caring role are more likely to develop networks that enabled them to bridge 'multiple social worlds' (p.278) than non-carers even though they may have greater restrictions in their everyday life. However, later in the care trajectory carers are no different to non-carers in terms of network change. Examining the data, most bonding ties were kin whereas most bridging ties were friends (66%) rather than other associates such as neighbours or health professionals. This study does have limitations, in that it does not uncover the precise membership of the carers' networks across the two waves and how or why particular ties became redundant or were activated. However, the findings from both of Roth's studies are interesting and show the potential for an expansion and change in the network structure as carers take on the role. In terms of considering the role of social capital, the role of bonding social capital in those care networks associated with kin aligns with Keating and Dosman's (2009) view of social capital as integral to the family-based care network. Roth's (2020) findings that friends act as bridging networks with greater access to wider resources including support and information that may aid their role also links to the Keating and Dosman (2009) study where the presence of friends and more distant kin enabled access to community resources.

In a UK based study (Egdell, 2012a; Egdell, 2012b; Egdell et al., 2010) 13 carers of family members with dementia were interviewed and a small number (n=5) also completed diary data. Recruitment was from three contrasting socio-economic areas to consider the impact of the surrounding clinical, cultural, and social infrastructures

on the carers' support networks. The data identified three routes to support as follows: guided routes, organic routes, and chance routes (Egdell, 2012a). The data uncovered that the networks were limited, fragile, and dependent on carers utilising their available resources (social, emotional, cultural, or economic) through their caring trajectory (Egdell et al, 2010). The variations in support and access impacted on the carers' experiences. For some pre-existing networks were utilised although not all had these networks. Others developed new networks to respond to their situation. In some cases, formal services were used as a substitute for informal care. However professional support was challenged and rejected by some although in one case diagnosis was a turning point to seek formal support. For some there was little choice in becoming the main carer and their normative views on caring obligations alongside their ability to share or relinquish the caring role also impacted on the development of the network (Egdell, 2012b).

2.29 The Interface between Informal, Formal and Community Care

The carer is situated at the interface of the informal and formal care networks. As already described in section 2.26 the informal care network potentially contains close and distant kin, friends, and neighbours. Some may act as the main carer whereas other offer specific types of aid or assistance (Sims-Gould and Martin-Matthews, 2007). As the health of the care-recipient changes or evolves over time the care network can expand and may involve other paid, formal carers or organisations from the wider community. The evidence relating to these further dimensions of the network will be analysed to consider how this wider network is constructed and operates in the provision of care

2.29.1 Formal Care and the Care Network

Understanding the mechanisms of entry into formal care provision is important since it can help to consider how early intervention and detection might best be approached with the care-recipient and their carers. The role of the informal care network (i.e., family, friends, and neighbours) and health services in recognising the signs and symptoms of a progressive illness will necessitate interactions within the network and

across the networks. Understanding the initial stressful period as carers and care-recipients begin to interact and negotiate with the formal care system and develop contacts at the initial point of entry, will potentially impact on future partnerships of care and influence the overall trajectory taken. (Carpentier et al., 2010) used data from a longitudinal study of 60 carers to reconstruct how the care-recipient with Alzheimer's entered the care trajectory. Using content analysis based on a life course perspective (family history, linked lives, human agency, and organisational effects) a typology of five entry pathways was constructed from the analysis of the social networks, social dynamics and action sequences within the data. The pathways were determined by several key factors. Past experiences of the family where they already dealing with the care-recipient's existing health issues meant that for some links were already in place with health services. For others, watershed events triggered the family to recognise that the individual was unwell and access to health services was then quickly initiated. Organisational effects: in this case health services/health professionals involvement triggered diagnosis and this was often with a small, isolated network incorporating an older carer-care-recipient dyad. Complex trajectories with gentle negotiations; in this network those surrounding the care recipient had a lot of previous experience of dementia and could facilitate members of the network to agree how assistance and support should be sought and provided. Finally, complex trajectories with difficult negotiations; this was characterised by a long wait for diagnosis, conflict in the network and the carer having their own individual difficulties that added to the complexity of the situation.

2.29.2 Service Use/Uptake and the Care Network

In the studies examined a number considered how carers and their social or care networks might influence or determine the uptake and use of formal services. Another dimension of Carpentier's et al., longitudinal study was to determine the barriers and facilitators to service use (Carpentier, et al., 2008). The first interviews from 52 carers, early in their caring trajectory, were examined. The period at the onset of the carers' involvement, the care context, their experiences, or those of other social network members in aiding the care-recipient, alongside the formal and informal resources used, were covered in the interview. From the analysis it was found that the delay in

accessing formal services was a product of several key elements and were against the backdrop of the social history of the carer and care-recipients' relationship. Thus, the following were identified as particular factors affecting access to services; the care-recipients acceptance of their illness and the nature of their physical problems; the availability, suitability, and awareness of services; previous experiences of illness alongside the carers' practical knowledge and finally their social relations and tensions within their family networks. Such social representations were an outcome of the many inter-related features of the situational context of the unfolding illness narrative and any associated difficulties and conflicts that occurred were also shaped by the individual values and beliefs of the carer. They reflected the complexity of the family/care situation, the nuances of family interactions, individual choices, psychosocial difficulties, and sense of stigmatisation.

In a very different approach Hong (2009) considered the factors that might explain heterogenous variations in service use by different carers. By analysing the 2004, large scale National Long-Term Care Survey and Informal Caregiver data in the US, three main types of 'service use' by carers were identified; multiple service users; selective in-home service users, and light service users. The study used a latent class analysis on 1908 carer dyads and examined overall patterns of carer service use. To assess the range of formal services that support informal carers three services offering direct help were included: respite services; support groups, and household services. Seven longer-term services offering indirect support to the carer through direct support to the care-recipient were also included as follows: financial information/advice; adult day care; personal or nursing care support; meal deliveries; home alterations and access to assistive devices and transport services. The Andersen Network Episode Model (1995) offered a framework for analysis of service use within three domains: 1. Predisposing factors to service use. 2. Enabling factors that help secure services, and 3. Needs that reflect the frailty of the individual. Larger care networks reduced service use since assistance from the informal network reduces the need for formal input. However, higher levels of social support encouraged caregivers to use services so although receiving actual instrumental aid they also gained information about services through this support. This echoes the work of Dosman and Keating, (2009) and Roth (2020) in terms of wider networks enabling access to other resources through bridging social capital. Thus, the carers' network composition determined service use patterns

with the needs of the care recipient and carer also influencing service use. Thus, services may need differentiation to meet carers' needs and to enable the allocation and targeting of resources.

2.29.3 Informal/Formal Links and the Care Network

The relationships that exist between the formal and informal care networks in long-term illnesses are usually long-standing and can be pivotal in terms of the success of care provision, the impact on the care trajectory and the outcomes for the care-recipient their carer and the wider care network. Services are required that are centred on their needs and provide appropriate ongoing support. Understanding the nature of the social relationships between the informal and formal care providers and the processes integral to their success is important when considering the design and delivery of care services. Discussions across the informal and formal networks have been examined by Jacobs et al., (2016) whereas Groen-van de Ven et al. (2018) examined shared decision making. In examining four case studies Carpentier and Grenier (2012) focussed on the microsocial interactions of carers with their networks and formal care providers.

To examine the wider interactions of the informal care network with the formal care providers Jacobs et al. (2016) analysed the discussions that took place between all the potential informal–formal carer dyads in a care network. The characteristics of the carer, care-recipient and the wider care network were also considered. The findings also formed part of the study previously described (see Broese et al., 2016, in section 2.26.2). Data was obtained from 74 older care recipients about their carers who provided five defined care tasks, alongside the contact between all the carers identified. Using multi-level logistic regression on the informal–formal carer dyads, demonstrated that in 26% of the dyads discussion on care occurred. These discussions were more evident when both the informal and formal carers performed multiple types of tasks and more formal carers were involved (potentially indicating the increasing needs of the care-recipient). When the main informal carer was a co-habitant with the care-recipient and contact within each of the formal and the informal networks was high, there were also more care discussions. It was concluded that, when the care recipient lives alone, to ensure that discussions regarding care take

place where no discussion has been occurring, formal care providers may need to allocate a formal carer to link to an extra-residential carer. Groen-van de Ven et al. (2018) studied the care networks of those with dementia and particularly the challenges of shared decision making: The study recruited 113 respondents in 23 separate care networks. Central to this approach was the inclusion of the 23 care-recipients with dementia. Their informal carers (n=44) and their formal professional carers (n=46) were also included. Using this design gave voice to the individual with dementia and allowed a real understanding of the informal and formal network dynamics for each care network. Content analysis uncovered two major themes that impacted on the decision-making as follows: Adapting to the situation with the diminishing independence of the care-recipient, resulting in continuous changes to the network, changes in decision-making roles and a need to anticipate future decisions. Network tensions were also identified as different perspectives and interests combine requiring agreement about emerging problems and a necessity for information exchange.

To consider the micro-social processes and complexity of the linkages between the informal and formal providers), Carpentier and Grenier (2012) used four case studies (two daughters and two male spouses of different social classes) from their original study of those caring for a person with Alzheimer's. Although a small number of cases were presented these were chosen to exemplify how the carers established successful linkages to resources outside their informal network. Those selected had the largest number of professionals involved in the care network over many years. Using narrative fragments and interpretative analysis of the network and interview data obtained, it was possible to identify and 'explain the linkage process between formal and informal care services' (Carpentier and Grenier (2012, p. 1333). The findings established that the strongest links were based on social support, robust social relationships developed through trust and/or social recognition. Establishing mutual social recognition of their respective roles, enabled the professionals and the carers to develop their involvement and competencies. The carers also effectively drew on the experience of those in their professional and community networks but were careful not to over-burden the network members.

In the following two studies Jaglal et al. (2007), and Sims-Gould and Martin-Matthews (2010) considered the satisfaction of carers and care-recipients with formal care services within the context of their care/social network. Jaglal et al (2007) recruited a convenience sample of 267 care-recipient- carer dyads that were accessed via four community-based dementia care networks who provided a range of services. A survey approach examining the correlates associated with perceptions of the care processes were examined. Sociodemographic data, health information, the typology of the dyad's support network and the service use by the dyad were ascertained. The outcomes of care were examined through assessing satisfaction with the quality and quantity of services provided, the appropriateness, availability, continuity, and co-ordination of those services; awareness of services and experiences of the family physician and health care workers involved in care. Univariate and bivariate analysis and regression modelling approaches were used to analyse the process of care factors. The findings showed increased satisfaction with services was related to the family physician's understanding and awareness of dementia and the services available. It was also linked to the physician's ability to collaborate with the dyad to accept services. Satisfaction of their experiences with healthcare workers was higher if the carer had support at home and emotional support was available to the care-recipient from their social support network. Variations were found across the four community-based services, particularly in terms of the process of care factors and were related to the awareness among family physicians about the available services, and the dyads' experiences with health care workers. To examine the dynamics of family and paid care in supporting older people in the home Sims-Gould and Matthews (2010) applied their conceptual model of assistive care (Sims-Gould & Martin Matthews, 2007, see section 2.26.1 for more detail). They therefore aimed to focus on the various contributions within the care process from both informal and formal care providers. In-depth interviews were carried out with 56 family carers. Participants included family or close friends (these had a spousal-like bond or a very long-term established relationship with the care-recipient) who identified themselves as being a carer for an older person who was having or had home support for personal care in the last 12 months. Their conceptual model (Sims-Gould & Martin-Matthews 2007) was used to guide the analysis with direct care and assistive care forming two over-arching themes. In terms of direct care, two sub-themes emerged which were the instrumental aspects

(performing the tasks associated with care) and the affective aspects (which focussed on the relational dimensions between the formal care provision and the care-recipient). There was dissatisfaction with the instrumental aid provided by home support workers with a sense of helplessness in not being able to determine the type of care that was being given and the restrictive nature of the care plan. Over 75% of the informal carers commented on the bureaucracy of the services. Most participants emphasised the importance of the affective support given by formal carers to the care-recipient in terms of providing companionship, widening their social network and 'breaking up the monotony of being predominantly housebound' (Sims-Gould & Matthews, 2010, p.419). In terms of assistive care (the care provided between the carers), three themes emerged from the care worker assisting the carer and vice versa: The sub-theme of 'caring together' was exemplified by interconnected, reciprocal care between the informal carers and the home support worker. Thus, both the informal and formal carer benefitted from this. When assistive care was more unidirectional, this was related to the sub-themes of management and quality assurance and monitoring of the care provided. In terms of management the informal carer had to orientate new workers to the home and teach them about the requirements and preferences of the care-recipient. To ensure that care was appropriate and individualised for the care-recipient, the carer monitored and assured care activities as part of their assistive role. This study showed the bidirectional nature of care between the formal and informal sectors and how there is a constant interaction between the two as both provide direct care and/or assist in care.

2.29.4 Community Support/ Help Groups/Peer Led Support and the Care Network

The role of community-based support for carers and the position of that support in terms the carers' networks have been studied. Abendroth et al., (2014) of peer support for carers of those with PD, described in section 2.25, are also reflected in the findings of the following studies: Lauritzen et al.,(2019); Teahan et al. (2020); and West and Hogan (2020). Each of these were small qualitative studies that examined carer experiences of support groups.

Lauritzen et al. (2019) collected ethnographic data from four support groups and via semi-structured interviews with 25 carers of those with dementia living at home. In this study, using participant observation offered a unique opportunity to fully uncover the cultural contexts and complex social interactions and events that were taking place in the groups. Content analysis identified three themes. The first theme, emotional well-being due to peer and family support reflected the beneficial effects of peer interaction influencing the carers' outlook. Observational data from the groups noted how the carer interaction with each other was positive and appeared enthusiastic. As previously described by Abendroth et al. (2014) the group allowed the carers to discuss their problems, adding new perspectives and solutions to their situation. Membership of the groups also enabled the carers to improve family relationships and prevent family conflicts. The safety of the group allowed discussions on the impact and nature of the illness that may have not been had within the care-recipient's family. An emotional sense of togetherness, despite hardships was the second theme. Here carers expressed their love and the reciprocity of feelings between themselves and the care-recipient. However, as this was lost due to the illness friendships in the group became increasingly important. Finally, the emotional and ethical considerations in caring formed the third theme. This highlighted the shared understandings that were evident in the group as carers expressed concern and anger about society's reaction to the illness or to the care-recipients behaviour. Lack of respect by family and friends was felt to be a result of a lack of understanding about the illness. In the group carers openly shared their embarrassment and sorrow about this and visibly communicated emotional support for each other.

The role of the Alzheimer Café in Ireland in supporting carers of those with dementia has also been explored (Teahan et al., 2020). In this small study of nine family carers, semi-structured interviews were used with questions developed based on an ecological framework that considered the carer in terms of a wide range of interacting economic, social, and cultural systems. Thematic analysis led to the development of four main themes: Community; Atmosphere; Activities and Information. The Alzheimer Café provided an opportunity to be part of a community of those dealing with dementia. Various activities and connections fostered and developed this community. As previously described by Abendroth et al, (2014) and Lauritzen et al, (2019), the emotional support networks were a key element with advice and a common

understanding of the illness. The communal space offered an open, neutral venue where carers could openly discuss their issues. Furthermore, attendance and participation helped to reduce the social isolation of the carers. The atmosphere was important since it was welcoming, and the carers emphasised that this environment enabled them to discuss and explore dementia. The activities associated with the café allowed the carer and care-recipient to participate in these together and for many this had been an aspect of their lives that had changed or been lost due to the illness and social pressures. Information on dementia was provided through several means, including speakers and health professionals. The range of topics developed awareness of dementia care and the psychosocial elements that related to emotional well-being and self-care. Finally, in a small-scale study, to examine the benefits of attending a dementia support group, West and Hogan (2020) interviewed 14 informal carers of dementia patients about their experiences of the groups. Three themes were identified. The first was an opportunity for social interaction containing two subthemes; stimulation is offered by the group and providing a relaxed atmosphere of support. The second theme was sharing experiences and information and the third theme was initiating attendance requires strength.

The studies reviewed shared core elements but focussed on different dimensions of the carers' experiences in the groups they encountered. It is evident that the social interactions (West & Hogan, 2020) allowed the development of beneficial social relationships (Abendorth et al., 2014) with the resultant emotional support obtained positively impacting on the wellbeing of the carer and care-recipient. (Lauritzen et al., 2019, West & Hogan, 2020). The sense of community, ambience, and range of support available also appeared to foster this (Teahan et al. 2020; West & Hogan, 2020). There also appeared to be a shielding effect away from the stigma associated with a chronic debilitating illness.

2.30 Part 2 Summary

These studies demonstrate that there are intricacies in family care provision which can be impacted by gender, health, marital status, ethnicity, or age of the carer and/or care

recipient and are a function of the activities of those in the network. The strength of this care network research lies in the widening of the approach to understand the interactions of multiple individuals working and collaborating to provide care in the wider informal and formal contexts. The dynamics of family life and informal/formal contact are also revealed, and this gives a different dimension to and perspective beyond the carer/care recipient dyad. Although the family remain a consistent presence, the expectation that those requiring care in the community are surrounded by close and extended family and friends who will be available and willing to provide care is an assumption that fails to acknowledge the complexities of informal care. Caring in the community potentially involves a range of family members through direct and assistive help. The heterogeneity of informal care with a recognition of differing family structures and family dynamics needs to be explored further with a greater understanding to inform policy and health and social care practice. The role and experiences of informal carers are directly affected by Government policy that has not fully recognized the increasing needs and demands of the older population alongside the impact of austerity on social care. Close-family ties and reliance on the family do not necessarily ensure the best care outcomes for frail older adults or their family members. Although care work has not entirely been transferred over to families, friends, and neighbours the responsibility for care has most certainly shifted to the informal networks.

Furthermore, paid formal care and its role in support of and as an adjunct to family care needs further exploration. Understanding how successful and effective links are formed between the informal and formal sectors can inform health and social care practice. The growth of TSOs in overall care provision is another part of the care sector that requires further study in terms of its position in the care network and its role in supporting informal carers. In the generalisability review presented in part two, the findings from the studies are principally derived from outside the UK and therefore do not necessarily reflect the care context in this country. Only the studies by Egdell (Egdell, 2012a; Egdell, 2012b; Egdell et al., 2010) Katbamna et al. (2004) and Rutherford et al. (2014) have closely examined carer networks in the UK. In terms of publicly paid formal care and carer associated payments, these are still provided in the UK and any comparisons can be difficult given that economic conditions can vary

across developed countries, with different institutional structures and differing approaches to welfare and health and social care delivery. Thus, the proportion of older adults obtaining paid formal care may be smaller in some countries than others. For carers of those with PD, the heterogenous presentation and protracted nature of the disease can lead to a prolonged and difficult care trajectory that will involve both informal carers and potentially a diverse range of formal care providers. However, there are no studies in the UK, on the social networks of those carers providing informal care for individuals with PD. Thus, the structure and function of their networks along with the perspectives and views of this group in relation to the effects of those networks on their caring role have not been examined.

Therefore, the questions that emerged from this literature review in relation to carers of those with PD and are addressed in this study are as follows:

- What are the forms, functions, and associations of carers' social networks?
- How do carers access and utilise the resources contained within these networks?
- How do their social networks impact on their caring role?
- What is the role of the health and social care sectors and the local community in shaping or developing carers' social networks?

The studies reviewed were diverse in terms of their methodological approaches. Large cohort studies enable greater generalisability, whereas longitudinal studies facilitate examination of temporal changes. Smaller qualitative studies give an in-depth and unique view of care scenarios and network phenomena. Using a case study methodology, this study will incorporate social network analysis and qualitative data to explore network structures and practices giving an in-depth and complementary understanding of the network in action (Hollstein, 2011).

Chapter 3: Methodology, Methods, and Data Analysis

3.0 Part 1: The Methodology and Methods

3.1 Introduction

This chapter will discuss the constructivist and methodological approaches taken to undertake the study. In part one, social network analysis and how this informed the design of the case study will be described. A rationale for selecting a case study methodology that combined social network analysis and qualitative approaches will also be presented. The case study research design will be detailed alongside an explanation of how the data collection methods were constructed and refined. To determine the methodological approach, it was essential that the design focussed on the objectives of the study and the research questions. Determining the nature of the data and how it would be collected were central to achieving the objectives and answering the research questions (Gray, 2009b; Patton, 1990). The types of questions posed within this study were both exploratory and explanatory and case study research offered a means of investigating such questions (Patton, 1990; Stake, 1995; Yin, 2009).

In part two, the mode of data analysis using the Framework Method (Ritchie & Spencer, 1994; Spencer, et al., 2014) will be described to explain the steps taken to interrogate all aspects of the data. How the Framework Method facilitated the triangulation of the different data collection tools allowing a comprehensive synthesis of the component aspects of the data will also be explored. The application of the social support models developed by Kahn and Antonucci and Cantor (Antonucci, 1985; Antonucci et al., 2009; Cantor, 1979; Cantor, 1991; Kahn & Antonucci, 1980) to the data analysis, through the lens of Social Capital, as a means of structuring the analytical approaches taken to explore the data, will also be considered.

3.2 A Constructivist Approach

Social constructivism is a view where individuals seek to understand the world that they live in by developing subjective meanings of their experiences and these can be directed at objects or things (Creswell, 2009). It therefore considers multiple realities with a subjectivist epistemology (i.e., the researcher spends time in the field with the participants), and employs naturalistic methodological procedures (Guba & Lincoln, 1994). In embracing multiple realities, these are valued equally, are socially and historically constructed and are specific to individuals or groups (Bryman & Teevan, 2005; Crotty, 2003). Constructivist researchers will often focus on the interactions and processes that occur between people and the context in which they live. This enables the cultural, social, and historical context to be understood (Creswell, 2009). This interpretive approach is closely aligned with the aims of this study i.e., to understand and illuminate the place of social networks in supporting the carers role, and the processes associated with accessing the resources within those networks. Utilising mainly qualitative research methods with some quantitative elements will enable the carers' perspective to be elucidated. These methods align with the social constructivist approach.

For each carer their particular social and cultural context will be unique. In this approach, the subjectivist epistemology is underpinned by the recognition that the researcher and those participating co-create an understanding and meaning of the phenomena under study (Guba & Lincoln, 2005; Silverman, 2005). Thus, adopting this position aligns with a view that the carers in this study would share their personal, multiple realities that belong to their experience of being a carer in their personal social networks (Rodwell, 1998) and for each carer, the meaning of each experience and interaction within those networks would be unique (Schwandt, 1994). Therefore, the researcher's approach is to consistently aim to co-create knowledge with the participants whilst maintaining trustworthiness and authenticity (Denzin and Lincoln, 2013). Constructivism has the potential to initiate action and change through the development of greater understandings and increasing knowledge (Charmaz, 2006; Rodwell, 1998). Working with carers in the study was a privilege and it was important

that in my approach I continuously reflected on the process of the research, my findings, and experiences as I collected and analysed the data. This allowed recognition and acknowledgement of new perspectives (Guba and Lincoln, 1994). Engaging in self-reflexivity is a central tenet to the constructivist approach with the researcher analysing their influence and personal prejudices on the research process (Savin-Baden, 2004). My personal values will shape the research process as will the values of the carer. Thus, recognition of the mutuality of this shared relationship and the interaction that takes place is important. Working collaboratively with the carers, was central to the research and this was approached by developing a relationship based on respect and trust. Openness and honesty about the aims and conduct of the research and willingness to communicate and share information with each carer was central to this. Allowing a choice of setting for the dialogue that would take place was also important and allowed for a natural setting that aligns with a constructive approach (Rodwell, 1998; Denzin and Lincoln, 2013). Throughout the study, following sound ethical practices and consistently reflecting on the data and interactions with the carers facilitated this collaborative approach and shaped the interpretation of the data (Flick, 2018; Gray, 2009b). The principles and approaches used in designing and undertaking this study, were therefore underpinned by a social constructivist perspective.

3.3 Social Network Approaches and the Methodology

In choosing the methodology, the key aim was to examine the form and function of the networks of carers of those with PD and understand the nature of the transactions that take place within those networks. Thus, offering a useful insight into those processes that occur in relation to the caring role (such as discussions and exchanges of resources, information, and advice) (Perry & Pescosolido, 2010). Social network theory and analysis offered a means of examining the carers' social structures in a tangible way (Granovetter, 1973; 1983). By analysing these social relations and interactions it was possible to extrapolate social phenomena and gain greater understanding of the intricate interactions of the carers and those who formed their

informal and formal care networks (Borgatti et al., 2009; Hollstein, 2011). Social network analysis offered a quantitative approach that enabled construction of a detailed picture of the carers' networks. The empirical evidence is developing, and it indicates that qualitative approaches to networks offers alternative opportunities to study defined population groups whose circumstances may limit their involvement with larger more complex quantitative studies (Hollstein, 2011; Phillipson et al., 2001; Campbell et al., 2019; Ryan et al., 2014)

3.3.1 A Case Study Methodology

A case study approach appeared to offer an effective examination of the carers' social networks within each carer's unique context through a varied range of data collection approaches (Stake, 1995). Two components to the overall definition of the case study have been proposed (Yin, 2009). The first relates to scope of the case study and is defined as:

an empirical enquiry that investigates a contemporary phenomenon in depth and within its real-life context, especially when the boundaries between the phenomenon and context are not clearly evident (Yin, 2009: 18).

The second component relates to the technical aspects of the case study as follows:

the case study inquiry copes with the technically distinctive situation in which there will be many more variables of interest than data points and as one result relies on multiple sources of evidence with data needing to converge in a triangulating fashion and as another result benefits from the prior development of theoretical propositions to guide data collection and analysis (Yin, 2009: 18).

Within the case study, it was deemed appropriate to utilise qualitative approaches with additional quantitative elements that could offer an insight into social reality and a particular means of examining the egocentric networks of carers, furthering an understanding of the dynamic interplay between networks and individuals (Hollstein, 2011). However, to have a more comprehensive view of the networks in question and to delineate network structures and network size, it was possible to use diagrammatic representations (Borgatti & Lopez-Kidwell, 2011; Borgatti et al., 2009) from the

network data. Given that several complex and inter-related factors may also impact on the carers' social networks, capturing individual carer's biographical and related data also allowed for a fuller examination of the associated phenomena.

3.3.2 Exploring the Networks of Informal Carers of those with Parkinson's Disease as a Case Study

Several reasons led to the decision to focus on the carers of those with PD utilising a case study design. There is less empirical evidence on carers of those with PD compared to carers of those with Alzheimer's Disease and dementia. Furthermore, there are no detailed studies on the social networks of this group of carers. As described in sections 2.3-2.6, PD often has a prolonged and complicated trajectory, and the progressive motor and non-motor features may develop over a long period (beyond 10 years from diagnosis) (Greenland and Barker, 2018). Therefore, patients and their carers may have been managing and living with the disease for a significant period. The heterogenous nature of the symptomatology can lead to a difficult trajectory that can lead to complex debilitating physical problems and significant cognitive affects that may include dementia. The psycho-social implications of the disease and complex medicine regimes needed, particularly in the later stages, also add to the work of care and the burden of caring (Solimeo, 2009; Martinez-Martin et al., 2008; Schrag et al., 2006; Williamson et al., 2008; Ogugh et al., 2013) The role of the carer in supporting their family member with PD can be challenging due to the varied range of support that they may need to provide (Vatter et al., 2018; Hand et al., 2019) and the stigmatising manifestations of the disease (Solimeo, 2019; Gibson and Kierans, 2017; Caap-Ahlgren et al., 2002; Nijhof, 1995). Management of the disease from a health service perspective can also be complex since the heterogeneity of presentation often requires a multi-disciplinary approach (Read et al., 2019). Guidance from NICE (2017) and recent evidence has acknowledged that services do need improvement (Parkinson's UK, 2019; NHS England, 2019c; Read et al., 2019).

Utilising a case study approach for this group of carers enables their situation and context to be examined. The unique demands of care (as described in section 2.3-2.6) will potentially shape the informal and formal networks as the disease progresses. In

relation to health and social care, the availability and range of services that are (or not) available for this group will potentially vary, based on geography, local configurations, and accessibility, and this work will elucidate the aspects of these structures for each carer and across the overall study.

The case study was designed as a multiple-case design. Each case (based on each participant in the main study) formed a separate unit of analysis which allowed for individual investigation (Yin, 2009). For each carer there was a unique context within which their social networks operated. However, through careful typology and selection of cases based on theoretical and purposive sampling, it was possible to select relevant cases that furthered the development of explanations about the nature and utility of carers' social networks. In undertaking sampling in this way, the aim was not to achieve statistical generalisability but to ensure that the sample was meaningful theoretically (Mason, 2002; Silverman, 2005). However, it was noted that findings from a particular case study can disconfirm the emerging theories and this can be used to refine and elaborate on the final theoretical understanding (Yin, 2009). A fuller explanation of the sampling strategy is given later.

Classically, case study evidence can come from many sources including documents, archives, interviews, direct observations, participant observation and physical artefacts (Yin, 2009). Within this case study semi-structured interviews with participants, survey data including the collection of biographical data, network data (for the production of socio-grams), and assessment of the COPE Index (Balducci et al., 2008) alongside documentary evidence in the form of a participant's diary offered a complementary approach. Triangulation of both the quantitative and qualitative data offered a means of assessing 'the degree of convergence' (Patton, 1999, p. 1194) with an emphasis on considering the interpretations of the data from each source, alongside their different merits. Detail about each method of data collection and measures taken to ensure quality and credibility are discussed later.

3.4 The Study Design and Data Collection Approaches

Increasingly, it is being recognised that a dichotomous view of qualitative and quantitative approaches is limiting when examining the complexities of social life (Fontana & Frey, 2008). Using multi-layered approaches can enhance depth and breadth of understanding of social phenomena (Bazeley, 2004). Importantly the purpose of employing a range of approaches is to provide data that can answer the research questions, is guided by theory, and can truly meet the overarching goals of the research (Bazeley, 2004). A variety of data collection tools allows for a pragmatic consideration of the necessary approaches that are needed to fully and creatively elucidate the research questions (Patton, 2002). Both qualitative methods and network analysis offered a means of uncovering the complexities of the carers' relationships within the informal and formal networks whilst exploring the differences that might become apparent in different aspects of the network. Furthermore, this approach offered a means of further validating the findings and verifying the approaches in several ways (Gray, 2009b). Triangulation of the findings of the different methods, aids convergence of results. Complementarity is achieved from the findings of one method elaborating or enhancing the findings from another. Initiation, where a review of the research questions may be undertaken, is possible if there are contradictions in the findings across methods. Finally, development of the methods employed is also possible since utilising one method can develop or inform another method.

In examining the social networks of carers by employing different approaches offered a means of linking perspectives on both structure and agency. Therefore, data from the carers and their understanding of their networks alongside the detail of network structures was obtained (Hollstein, 2011). This was pragmatic, and the complementarity that resulted allowed a fuller and more detailed understanding of the research question (Gray, 2009b). A sequential approach (Creswell, 2009) was taken within each case, in that the structural network data was collected first, followed by the qualitative data. This aided development of the subsequent qualitative interview topic guide. Utilising the different tools had advantages since for each case it was possible to triangulate the findings, thus facilitating cross validation or potentially highlighted contradictory data (Jupp, 2006).

3.4.1 Methods: Designing the Data Collection Tools

The data collection centres on the ego networks of the participant carers. In examining ego networks, the data collected is defined by how the individual perceives and reports on their network (Wellman, 1979). For each respondent, network data was collected that examined the immediate personal contacts (alters) of the ego (carer's) network. The ego is in the centre of the network and the alters form ties with the ego. The combination of ego and alters and the ties connecting these together made up the egocentric network of the carer (Prell, 2012).

The data was collected in five ways:

1. A survey of biographical data
2. An assessment of carer 'coping' using the 'COPE Index' (Balducci et al., 2008)
3. Ego-centric network data using a questionnaire
4. A participant diary constructed to examine the carer's network interactions over a two-week period
5. Finally, a semi-structured interview with the carer

Copies of the initial pro-forma, COPE Index and name generator questionnaire can be seen in Appendix 3. The biographical data collected via the COPE Index and pro-forma included the following: time in the caring role; hours spent caring each week, age/date of birth; gender; health; relationship to the care recipient; occupational status and living arrangements in relation to the care recipient. This data was all based on factors known to be important determinants in managing the caring role (Balducci et al., 2008; Beesley, 2006; Hirst, 2004; Yeandle & Wigfield, 2011). The details, design, and rationale for the the 'COPE Index' (Balducci et al., 2008), the ego-centric network data using a questionnaire, the participant diary and the semi-structured interview will now be discussed.

3.4.2 The COPE Index

The original tool was validated in 2003 (McKee et al., 2003) and was designed to capture the role perceptions of carers of older people. The initial index was designed as a 17-item tool. In the original validation recognised instruments for criterion

validation (the General Health Questionnaire (Goldberg, 1988), the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) and the World Health Organisation Quality of Life (World Health Organization, 1998) were used. Initially data was collected from 577 carers across five European countries including the UK. In the first validation two components, negative impact, and positive value, were consistent with the criterion measures. The quality of support aspect was less consistent in this preliminary validation. However, a further validation involving 5,923 carers across six European countries has enabled further refinement of the tool which now offers two subscales; one measuring negative impact of caregiving (seven items included) and one measuring the positive value of caregiving (four items included) and a further four items measures quality of support (Balducci et al., 2008; McKee et al., 2003). For this study, the data from the initial questionnaire, based on the COPE Index, offered a preliminary screening mechanism to identify carers' positive and negative perceptions of their role. and the quality of support they receive.

3.4.3 Egocentric Network Data

Social network data can be obtained on entire organisational structures or communities and there are numerous studies that have undertaken such an approach (Rowson et al., 2010; Wellman & Wortley, 1990; Prell, 2012). However, for the purposes of this study, the carers' networks were examined and the individuals (alters) that they were connected to in their social networks identified. It was also possible to examine attributes of each alter. Close-ended questions were used to elicit very specific responses to name generator and name interpreter questions (Marsden, 1990; Oppenheim, 1992; Prell, 2012). To elicit alters within the carers' network several different name generator questions were used. However, these needed to be carefully crafted if the original research questions were to be examined in greater depth. Added to these questions were name interpreter questions that gathered further information about the characteristics of each alter in the network.

A questionnaire was used to obtain the necessary quantitative data related to the participants' social networks. The questionnaire design followed guidance from Oppenheim (1992). The questionnaire was administered at the beginning of phase two of the study to elicit the quantitative network data. This was carried out with the

participants identified to undertake the study. The considerations given to the development of the questionnaire on the carers' social networks are detailed below.

3.4.4 Designing the Network Questionnaire

In designing the questionnaire, theoretical consideration was given to the social capital and social network literature alongside the research questions of this study. To fully elucidate relational properties within the carers' networks it was essential to consider the various networks that the carer would interact with (Prell, 2012). In terms of designing and phrasing the questions several factors needed to be considered. Firstly, the research intends to examine the form, functions, and association of carers' social networks alongside how carers access and utilise the resources contained within these networks. Thus, the focus of this work was to examine carers' personal networks with an emphasis on the utility of those networks in their caring role. Therefore, the name generator questions needed to be specific and detailed enough to fully elicit all the multiple relationships that exist in the carer's network. The interpreter questions elicited information on alter attributes (role and relationship) and tie properties (including tie strength, frequency of contact and intensity). Further information pertaining to the typology of those ties was also ascertained. This included positive affects; supportive or resource exchanges; co-ordination and any negative aspects including conflict (Marsden, 1990).

A network name generator has been devised to capture those who individuals turn to and discuss 'important matters.' This has been regularly used since it first appeared in the United States, General Social Survey in 1985 (Burt, 1984, 1985). This approach has been attractive since it aims to capture the structure and function of those networks that people use for support and in times of crisis. Furthermore, this all-encompassing approach has been viewed as a means of reducing respondent-burden when completing such questionnaires since to examine further detail and specificity requires more questions (Marsden, 1990). However, there has been criticism of this approach, with a view that 'important matters' and the achievement of a particular outcome may only be linked in a tenuous way. Thus, arguments have been forwarded to phrase questions that will best elicit data on the topics that truly reflect those

important to respondents in the study and directly associated with the outcomes of interest (Bearman & Parigi, 2004). The functional specificity hypothesis for social networks proposes that social network ties are activated based on problems or tasks most pertinent to the individual to garner support and resources (Simons, 1984; Sutor, et al., 1995). Empirical work by Perry and Pescosolido (2010) examined the networks of those with an acute mental health episode. Using name generator questions, they compared those named by the respondent as individuals with who they discuss 'important matters' and those with who they discussed 'health matters'. A significant overlap in the networks was found between the two. However, different characteristics were found across the two network groups with those in the health matters group having greater experiential homophily. There are four key approaches to elicit and delineate personal networks and in particular the supportive aspects of those networks (McCallister and Fischer, 1978; Milardo, 1987; van der Poel, 1993). These are: the interaction approach; the role relation approach; the affective approach and the exchange approach.

The interaction approach offers a means of identifying those individuals that the ego is in contact with over time. This approach has been criticised in terms of the validity and reliability of the data obtained since there is often little correlation between everyday contacts and those that individuals value as the most important (Marsden & Campbell, 1984). Furthermore, the stability of the network measures is also questioned since test-retest data from the same respondents demonstrates wide variations in those alters named from one day to the next. The role-relation approach concentrates on culturally or socially defined relationships (e.g., family, neighbours, friends). However, van der Poel (1993) argues that this approach limits true delineation of a personal network since there is significant variation across individuals in the specific content of the relationship. The affective approach has a distinct subjective dimension in asking for the names of those people with whom the ego has a close personal relationship or are particularly important to them (Wellman, 1979). The criteria for 'a close personal relationship' are not specified and therefore individuals are left to define this for themselves. Those concentrating on normative or socially constructed expectations may omit an important alter. Consequently, it is difficult to compare data from different egos since the nature of this approach will almost certainly produce differences. The exchange approach, however, concentrates on 'rewarding

interactions' (McCallister and Fischer, 1978). Thus, where an exchange takes place in a social interaction those alters involved in the exchange will be particularly important influences in the egos network.

Van der Poel (1993) believes that this approach has two advantages; firstly, the named interactions relate directly to social support and secondly the interactions are couched in specific terms that are not ambiguous therefore reducing the likelihood of respondents interpreting the questions differently. The questions in this study needed to generate data that will provide a rich and detailed picture of the carer's ego-centric network that also uncovers nuanced detail of the support that carers receive in their role. Such interactions that are supportive in this way may be considered as 'social support.' Thoits (1995, p. 64) defines social support as 'functions performed for the individual by significant others such as family members, friends and co-workers.' These functions typically include emotional aid, instrumental aid, and informational aid (House et al., 1988; Thoits, 1985). It is argued that there can be some disadvantages in using this approach. Namely, where there have been no recent supportive interactions from a relationship this may not be included in the data collected. As such in trying to delineate support networks it was important to draw on the potential supportive nature of any relationship. Thus, the questions used are couched to offer scenarios where potential help or support might be needed (McCallister & Fischer, 1978; van der Poel, 1993). Drawing on the work of McCallister and Fischer (1978) to obtain a full range of personal support networks, Poel (1993) tested an original ten-item instrument to produce a subset of name generators which allows for a quick and reliable means of obtaining the substantive components of an ego's personal support networks. The original ten name generators were split to include questions on emotional support, instrumental support, and social companionship. These questions were formulated to ascertain potentially supportive relationships (i.e., 'main effect'). The questions were based on specific criteria in relation to the nature of the exchange be it emotional, instrumental support or social companionship.

Van der Poel (1993) administered the 10 questions to 902 people (aged between 20 and 72) and resident in the Netherlands. Analysis of each name generator with an explanation of the variance observed demonstrated that no single item could succeed in covering all role relationship categories. Undertaking further global analyses found

that five name generators appeared to be the most efficient number to elucidate the personal support network. Based on this work the first five name generator questions included in the network questionnaire for this study are those derived by van der Poel (1993). Given that individuals activate personal ties in a selective and purposive manner (Simons, 1984; Sutor et al., 1995) the final name generator questions (originally numbered 6-9, which became 6-10 after the pilot) were formulated to directly address the nature of support mechanisms for the carer in terms of who they might turn to discuss more generally 'important matters' and then more specifically who they might rely on for their own health and finally who they may rely on in terms of the caring role. These questions that are specific and aim to elicit data about the functionality of those networks most associated with the caring role are important for this study. The original questions suggested by van der Poel (1993) therefore offered an instrument to delineate personal support networks; however additional name generators were needed to answer specific questions that relate to support and the caring role.

The order in which name generator questions are asked can affect responses (Burt, 1997; Pustejovsky & Spillane, 2009; Rowson et al., 2010) since earlier questions may have a priming effect. As such participants were asked several questions that examined their social networks in a range of contexts before asking about those networks most closely associated with their caring role. Following on from the pilot study (see section 3.6 for details of this) the questions to elicit carer social network data including the nature of the support were formulated as follows:

Emotional Support

Q1. Suppose you need advice with a major change in your life, for instance changing jobs or moving to another area. Whom would you ask for advice if such a major change occurred in your life?

Instrumental Support

Q2. Suppose you need help jobs in or around the house for instance holding a ladder or moving furniture. Whom would you ask for this kind of help?

Q3. Suppose you need sugar or something like that and the shops are closed, or you need a piece of equipment. Whom would you ask for this kind of help?

Social Support

Q4. With whom do you go out once in a while, for instance shopping, going for a walk, going to a restaurant or to a movie?

Social Support

Q5. With whom do you have contact with at least once a month by visiting each other for a chat, a cup of coffee a drink or a game of cards?

Emotional Support

Q6. Who are the people in your life with whom you discuss important matters?

Carer Specific Support

Q7. Who, among all the people in your life, do you talk to about your health? Who are the people that you can count on when you have a physical or emotional problem?

Q8. Who, among all the people in your life, do you talk to about the health of the person you care for?

Q9. Who, among all of the people in your life, do you talk to about your caring role?

Q10. Who are the people that you can count on when you need some sort of support in relation to your caring role?

Further information is asked about each alter to ascertain key information that further illuminates features of the ties between the ego and the alters (Wellman, 2000). Determining the strength of each tie is measured by the question *How close is your relationship?* A scale from 1, extremely close to 3, not close at all was included to determine the strength of the tie. The work of Granovetter (1973) examined the strength of ties. The 'Strength of Weak Ties' postulated that where a social circle consists of dissimilar persons the circle is diverse with access to a greater range of information that can be readily transmitted, whereas 'strong ties' tend to be between similar individuals such as family and close friends. In this case there is less

opportunity for the flow of new and varied information among the group. However, the presence of strong ties is also viewed as supportive and influential in a network structure (Halpern, 2005). In designing the name generator and interpreter questions in this way it is envisaged that it may be possible to distinguish whether the strength of the ties determines the nature of the social exchange and the type of support received by the carer.

The nature of the relationship i.e., family, friend, neighbour, colleague, qualified or unqualified health worker or volunteer ascertained the diversity and nature of the social network that aided the carer in their role. Understanding the importance of family and friends in these support networks alongside the role of health care practitioners in the networks offered the potential to juxtapose the range and diversity of differing roles within the support network. It was interesting to gather potential data on the involvement of health workers and those in Third Sector Organisations (TSOs). It was envisaged that their role may be as confidantes, sources of information, and sources of referral to other practitioners (Wellman, 2000). Examining the potential role of health care provision in the social network structures of carers in this way also offered the opportunity to understand 'linking social capital.' (Sretzer and Woolcock, 2004).

Access or frequency of contact is a further key measure. This was addressed by assessing face-to-face contact, frequency of telephone contact and distance to travel to one another. Frequency of face-to-face and phone contact were measured as follows daily, weekly, monthly, every few months, yearly or longer. Distance was measured in minutes from 0 to any limit with varying distances in-between. Following on from the pilot, it was also evident that electronic means of communication would also need to be included i.e., SMS, email, Facebook™, and other means of social networking. It is widely recognised that confidently measuring the total number of people that an individual knows is very difficult and time consuming (Fu, 2005). Therefore, the construction of the questions needed to consider respondent fatigue since in trying to elucidate comprehensive network data the list of questions can become long and unwieldy. In a closed or fixed boundary study where all members of the network are known (e.g., in a workplace) a roster can be used to elicit information on each person in the network. However, when examining ego-networks there is normally no boundary and free recall questions are used as name generators. Within

some studies a fixed number of name generators (fixed choice, limiting the number of names that can be given) are preferred to an open-ended number (free choice), although fixed choice approaches have been criticised as being restrictive, with the potential to artificially restrict the numbers within the network and therefore lead to error (Wasserman & Faust, 1994). Free-recall techniques are often used to examine ego networks where there are no pre-determined boundaries (Prell, 2012). For some the use of a single name generator helps to limit interview time and reduce interviewee burden. However, Marin and Hampton (2007) argue that this limits the full range of social support. In terms of recall, a fixed choice in terms of how many names can be listed to an upper limit of six was given for each question. This was to ensure that the broadest range of support was captured.

3.4.5 The Diary

The diary offered a further source of network data over a defined period in this case two weeks. Utilising a diary offered a means of examining daily contacts, and the social support exchanges associated with those contacts over a period, and in a contextual manner (Marin and Hampton; 2007). This also helped to overcome the issue that network generators do have the disadvantage of difficulties with recall and a bias towards 'stronger ties' (Fu, 2005). Fu (2005) compared the use of a single-item survey question with a contact diary. The single-item measure did differentiate individuals and corresponded closely with complex network measures. It was simple and straightforward to administer, thus, it was suitable for large-scale survey methods. However, the data obtained from the diary was detailed and sophisticated and offered a greater insight into the circumstances of the contact and the nature of the ego-alter relationship. Although Fu, recognised that the use of a diary can be time-consuming for the respondents and requires commitment he also acknowledged that the data obtained can be invaluable (Fu, 2005). He states, 'over time, it can become the most comprehensive and penetrating research instrument for measuring personal networks, which also shows the changes that shape and reshape the network structure' (p.184). The use of a diary within this study offered another dimension and window on the networks of the carers involved. Therefore, this added means of data

collection offered complementarity (Gray, 2009b) to the name generator questionnaire.

After reviewing the literature, and in tandem with the network name generator the diary designed for this study took the form of a solicited diary. This however can cause some tension since it is important that the participants can complete the diary using their own language and concentrating on events that are important to them (Alaszewski, 2006). The design of the diary was carefully considered. The wording of self-report items used unambiguous language that was appropriate for the target group i.e., carers (Nezlek, 2012). The diary was structured and included clear instructions for completion (Alaszewski, 2006). A page to record each contact was designed and allowed the respondents to log any social contact be it with family, friends, acquaintances, health professionals or strangers. The participants were encouraged to include diary entries that focussed on their social interactions that directly related to their caring role. Each page had an easy to complete section that included the first name of the alter, who initiated contact, the typology of the social interaction and the place and duration of the contact. Technology offered the potential for several methods to be employed in maintaining the diary. Although a pre-designed paper diary was made available, respondents were also given the opportunity to complete this using electronic methods which offered an alternative for the participants. This decision was taken because of the outcomes of the pilot study (Jacelon & Imperio, 2005). The introductory pages of the diary can be viewed in Appendix 4.

Participants were asked to complete the diary over a two-week period before the semi-structured interviews took place. The length of time needed to be considered since this activity may become burdensome (Corti, 1993). Jacelon and Imperio (2005) found that two weeks was an optimum timeframe in their study of participant diary use in older adults. In their study this allowed time for the participants to feel comfortable with the process of using the diary without it becoming a chore. They noted that, increasingly, entries became more detailed over the period. There are caveats in using diaries. Each respondent needed a reasonable level of literacy in English and as such this did have the potential to limit or restrict participants who were recruited to the study (Corti, 1993). Developing a rapport with participants, taking time to explain the diary and following sound ethical practice, facilitated the process and aided participant

upkeep of the diary (Elliott, 1997). During the study three participants chose not to keep the diary but were happy to recall contacts over a two-week period with myself prior to the final interview.

3.4.6 The Semi-Structured Interviews: Adapting the Diary –Interview Method

The diary-interview method as described by Zimmerman and Wieder (1977), offered a means of linking the diary data (and the network generator questions) with the final semi-structured interview. Given the inclusion of the network generator data in this study, this method was slightly adapted. Four stages were involved as part of this approach

Stage 1: The diary was introduced and explained during the first meeting when the name generator questions were completed. This allowed any questions and answers about the diary to be addressed.

Stage 2: The carers completed the paper or electronic diary, normally over a two-week period and then using a stamp addressed envelope or email, they returned the diary.

Stage 3: The diary was read, and a preliminary analysis undertaken. This included the production of a sociogram of all contacts, a description of the role-relation of each contact, and counts of the interactions the contacts made, alongside key features of the interaction and its significance in terms of the caring role. Simple sociograms were also produced from the name generator questions. The UCINET programme (Borgatti et al., 2009) was used for these visual displays.

Stage 4: The sociograms from the initial ego-centric and diary data were then used to guide the semi-structured interviews. An example of a sociogram from the interview can be seen in Appendix 5.

3.4.7 Utilising the Sociograms and Diary Data for Participant Visualisation

This sequential approach in collecting the data offered the benefit of visualisation and member checking of the data with participants as each case progressed. On completing the network generator questions and the diary data, the resultant sociograms from this data were examined. This gave time to ascertain key alters and

their role to the carer. The diary data also offered a 'snapshot' of time in the life of the carer and their network interactions on a day-to-day basis.

Therefore, as described by Zimmerman and Wieder (1977), the diary did act as a log that could be used for the interview, whereas the socio-grams offered a means of visualising the personal network. At interview this offered a reflexive approach (Giddens, 1994; Rowson et al., 2010) that had the potential to lead participants to re-define or re-order their networks since the diary-interview method offered a 'slower – paced' approach (Bartlett, 2012, p. 1722). Furthermore, the socio-grams and the diary entries did offer a means of adapting and nuancing each interview in advance. These approaches also aided 'later conceptual structuring of the interview' for analysis (Kvale & Brinkmann, 2009, p. 131). As described in other studies (Campbell et al., 2019; Ryan et al., 2014), the carers reflected on the diary and sociogram data at interview and this allowed a greater focus and consideration of those named in the network facilitating the collection of rich data.

3.4.8 Conducting the Semi-Structured Interviews

The semi-structured interview can offer a 'powerful method' for gaining an in-depth description of social phenomena (Yeo et al., 2014, p. 178). The interview was conducted as a conversation (Kvale & Brinkmann, 2009). However, as already described, the diary data and sociograms offered a structure to the questioning and a means of visualising the initial data. These approaches therefore combined 'structure with flexibility' (Yeo et al., 2014, p. 183). To design the semi-structured interviews Mason's (2002) guide to develop interview questions was used (see Table 5). The structuring of the guide concentrated on illuminating the roles of key alters and that of both health and social care in the network. Therefore, data was collected around the topic area defined by the research questions but gave the carers flexibility to raise

Table 5: The Interview Guide as Developed from Mason (1992)

Topic of Interest	Questions/Approach
Summary and clarification of network generator and diary data	Identifying key alters from the diary and name generator data. Utilising visualisation techniques. Clarifying roles and support. Adding names/altering the sociograms
Alters identified as supportive	<p>Can you tell me more about [the people] you've mentioned in your diary/network...</p> <p>What does [name from diary/network] do to support you in your caring role</p>
Alters identified as hindering	<p>Can you tell me more about [the people] you've mentioned in your diary/social network...</p> <p>What does [name from diary/network] do to hinder you in your caring role</p>
Carer strategies	<p>How might you approach (name of group from diary/network) for support?</p> <p>Can you give me some examples of when you have asked for help? Who did you turn to?</p>
Impact on the caring role	<p>Which (name of group from diary/network) has the most positive effect on your caring role? Can you explain the reasons for this?</p> <p>Which (name of group from diary/network) has the most negative effect on your caring role? Can you explain the reasons for this?</p>
The role of the health and social care sectors and the local community	<p>Can you tell me more about how (named health/social care personnel) support you in your role?</p> <p>How do TSO organisations (use name if included) support you in your role?</p> <p>In what way have health/social services/TSOs shaped your social networks</p>
Change in networks over time	<p>If we look at your social networks now (show diagram) –who wasn't part of your network before you began your caring role.?</p> <p>Can you tell me if anybody has become more important to you because of your caring role?</p> <p>Can you tell me if anybody has become less important to you because of your caring role?</p>

those areas most important to them. In this way it enabled the carer's true perspective to be ascertained.

3.5 Ethical Considerations and Ethical Approval

A study of this nature is open ended with emergent and unexpected outcomes. It also entails direct personal contact between the researcher and participants and therefore has the potential to pose ethical challenges (Patton, 1990). To ensure the rights, dignity wellbeing and safety of the participants, ethics approval was necessary. The carers as participants are potentially a vulnerable group and research could be intrusive and they could be open to exploitation. As a study that accessed carers via networks outside of the NHS, it did not require ethical approval via an NHS Research Ethics Committee. An application for ethical approval was therefore managed via the University of Hertfordshire Ethics Committee for Nursing, Midwifery, Social Work, Criminal Justice and Counselling (see Appendix 6 for the confirmation of approval). Informed consent is a cornerstone of such participatory research. The participants' needs took precedence within the study. Carer information sheets were designed to clearly articulate the aims and conduct of the research. To ensure best practice these sheets followed University of Hertfordshire protocols alongside National Patient Safety Agency (NPSA) and National Research Ethics Service (NRES) (NPSA & NRES, 2011) guidance. The contact details of the researcher were made available on the initial information sheet so that participants could discuss the nature of the research and have their questions answered before they decided to complete the preliminary questionnaire and participate. In conducting research with human participants, the ethical principles of non-maleficence, beneficence, justice and autonomy should underpin the work. Throughout the study, careful consideration was given to these principles (Hopf, 2004).

To facilitate informed consent (Hammersley & Traianou, 2012), the construction of the participant information sheet (see Appendix 7) and fliers were carefully considered to ensure that the information was clear and unambiguous. Approval of use, via the University of Hertfordshire Ethics Committee for Nursing, Midwifery, Social Work,

Criminal Justice and Counselling, was sought before distribution. Each outlined the nature of the study and what would be involved for any participant (completion of an initial questionnaire with the possibility of the completion of a diary and two one-hour interviews as follow up). A statement inviting carers over the age of 18 years old to participate in the study and the potential benefits of participation (e.g., the potential positive outcomes for carers in the future) was also included. Flexibility was stressed in relation to the location of any interview that might take place. A direct line number and email address for the researcher (and supervisors) at the University was listed for contact. Reference was made to ethical approval and the University of Hertfordshire logo was added. Approval of the design was also checked with the University's marketing department. After the interview carers were also directed to wider support in case, they needed to seek further emotional support. All those who agreed to take part gave informed consent and they all signed a consent form (see Appendix 8). They were informed that they were able to leave the study at any time. During each phase of the study, the purpose was reiterated and consent to proceed confirmed. The location of the interviews was decided by the carer, although most took place in the home, three were conducted in a café chosen by the carer.

During the interviews, I was conscious of my role and the potential balance of power that might lead to the carer feeling disempowered and their involvement as tokenistic (Carter & Beresford, 2000). It was important to recognise that discussing their role and current situation had the potential to cause distress. Two carers did become tearful during the interview as they reflected on their lives and their disclosures were possibly cathartic (Morse, 2001). I offered to stop the interview and encouraged them to seek further support. Both continued with the interview. At one interview, the care-recipient wished to contribute and although the interview continued, I explained that I would not be able to utilise their comments in the data analysis because ethical approval was based on carer data alone. I was conscious of my Registered Nurse status, and this was discussed with the carers, and I also clarified my role as a researcher. Where my opinion was sought about medication or a treatment option, I referred the carer back to the relevant health professional involved in their care

3.5.1 Confidentiality

Confidentiality and anonymity were maintained throughout the course of this study. Data was anonymised and any identifying information about the carers redacted (Anderson et al., 2006). The carers were informed that their real names would not be used in the Doctoral dissertation or in future publications. It was also explained that any data collected would be kept on a secured encrypted computer with access only available by myself as the principal researcher. Any audio data would be destroyed on the completion of the Doctorate. They were also informed that anonymised data would be kept for five years post submission. Data management throughout the study has followed the University of Hertfordshire's Data Management policy as required by the Data Protection Act (1998) and more recently the Data Protection Act (2018) and General Data Protection Regulation (GDPR) (Information Commissioner's Office, 2018)

3.6 The Pilot Study

To test and evaluate the proposed study design, a pilot study was undertaken. Undertaking a pilot study offered an opportunity to pre-test research instruments and should be viewed as an element of good study design (van Teijlingen & Hundley, 2001). The Public Involvement in Research Group (PIRG) based in the Centre for Research in Public Health and Community Care (CRiPACC) were approached to provide feedback on the research proposal and to add commentary on the design and format of the data collection tools. Their discussions and input were extremely valuable. The group were also approached to take part in the pilot study but were unable to commit to taking part at that time. However, access was permitted to the University's staff carers group. This group offers support to any member of staff who has caring responsibilities. A request to this group was made and two carers volunteered to undertake the pilot.

One male and one female carer both in their 50s participated. Both were working full time. One participant was caring for both parents. One parent was now living in a nursing home with advanced Alzheimer's disease. The other with early signs of

dementia, still lived alone in the family home one hours' drive from the carer's residence. The other participant had an adult son with profound physical and learning disabilities. The son was living at home with full-time, paid, formal care support.

3.6.1 The Cope Index

The pilot confirmed that the Cope index (McKee et al., 2003 and Balducci et al., 2008) offered a means to open-up a dialogue between the carer and myself as the researcher about the care giving relationship (normally this would be a health/other professional). It also offered a means of assessing the carer's view of their situation and their specific areas of need by scoring the sub-sections of the index in terms of the negative impact, positive impact and quality of support in their caring role

3.6.2 Piloting the Name Generator Questions

The name generator questions were central to collecting the initial ego-centric data and were used successfully to produce egocentric socio-grams. During the interview these diagrams were particularly valuable and added a reflexive dimension to the data collection process (Savin-Baden, 2004). Using the questionnaire was repetitive and the potential for respondent fatigue was evident. Therefore, in the main study I consistently tried to remain focussed with an effort to limit extraneous discussion so that the minimum time was taken to complete this. In discussing the questions during the pilot, a question on electronic contact with alters in the network was needed and Question 9 was too detailed. Therefore, this was changed from:

Q.9. Who, among all of the people in your life, do you talk to about your caring role? Who are the people that you can count on when you need some sort of support in relation to your caring role? to

Q 9. Who, among all of the people in your life, do you talk to about your caring role ?

Q.10 Who are the people that you can count on to support you in providing care?

3.6.3 Piloting the Diary

Both were given a paper version of the diary. The diaries were maintained for 14 and 16 days respectively. However, one participant did not find the layout of this satisfactory and designed their own version with the same headings on an Excel™ spread sheet. Consequently, the alter data from this diary was extensive. It was interesting that during this period the care recipient had been in hospital for a brief time due to a fall. Although, this was a short timeframe, the entries in the diary at that point were particularly insightful in relation to those alters who were central to the caring network. The daily log of activity with a brief commentary and details of the relationship with each alter was invaluable and it became apparent that this mode of data collection had some real potential to collect rich, time specific detail.

3.6.4 Piloting the Semi-Structured Interview

The timing of the semi-structured interview to elicit and explore the social networks of the carer in much greater depth was between 1 -1.5 hours which was as originally planned. An interview guide had been prepared that considered theoretical perspectives and the research questions (Kvale & Brinkmann, 2009; Patton, 1990). Although the questions were thematic and linked to the theoretical concepts associated with social capital and social network theory, on reflection the interview needed to be more systematic at times to ensure relevant topic areas were covered (Patton, 1990). Although the subject guide was broadly addressed, several avenues of inquiry became apparent particularly in relation to the involvement of TSOs within the network of care. Probes were helpful in eliciting further information or meaning (House et al., 1990). The interview schedule needed to give a greater emphasis on the role and relationships of those involved in the direct or indirect network of care. It was evident that viewing the personal ego network from the name generator questions and the diary entries during the interview was an excellent aide memoire (Elliott, 1997). This use of visualisation of the personal network was reflexive (Giddens, 1994; Rowson et al., 2010). Annotation of the socio-grams was also possible to examine temporal changes in the network and to ascertain further relationships.

3.6.5 Outcomes of the Pilot

Conducting the pilot study offered an opportunity to refine the methodological approaches (Thabane et al., 2010). Furthermore, it helped to highlight potential difficulties that could be altered prior to the main study (Treece & Treece, 1986). As a result of the pilot and before the main study commenced some minor changes were needed to the data collection tools as follows:

- Slight changes to the name generator questionnaire to ascertain the full network structure and to ensure that any functional specificity was properly addressed (Perry & Pescosolido, 2010; Simons, 1984).
- The diary was re-designed and simplified. Participants were offered the opportunity to complete an electronic version if preferred.
- The questions in the semi-structured interview were re-ordered. Priority was given at the start of the interview to exploring those alters or agencies that offer direct or in-direct means of support in relation to the carer and the cared for person.

Van Teijlingen and Hundley (2001) have detailed a rationale for undertaking a pilot study. Table 6 examines these considering the outcomes for this pilot.

Table 6: Rationale for Conducting Pilot Studies

(van Teijlingen & Hundley, 2001, p. 2)

Rationale for a Pilot	Outcomes from this Pilot
Developing and testing adequacy of research instruments.	Research instruments have been tested. The diary will be slightly re-designed and the opportunity to complete an electronic diary will be offered.
Assessing the feasibility of a (full scale) study/survey	The pilot indicates that the study is feasible and has the potential to uncover the intricacies of carer networks
Designing a research protocol	Although already completed this has enabled testing of the protocol.
Assessing whether the research protocol is realistic and workable	The protocol is realistic and workable
Establishing whether the sampling frame and technique are effective	Not established –only the full study can effectively test this.
Assessing the likely success of proposed recruitment approaches	Recruitment achieved via one small carers' group. However, it is not fully possible to extrapolate this to the final recruitment activity. Support of Parkinson's UK is likely to be invaluable in this respect.
Identifying logistical problems which might occur using proposed methods	Ensure clear completion and collection dates for the diary.
Estimating variability in outcomes to help determining sample size	Not applicable.
Collecting preliminary data	Data has been useful, although cases in the pilot are not caring for somebody with Parkinson's disease and therefore the data will not be added to that of the main study.
Determining what resources (finance, staff) are needed for a planned study	Not applicable.
Assessing the proposed data analysis techniques to uncover potential problems	Preliminary consideration given to this particularly in terms of thematic analysis.
Developing a research question and research plan	Allowed a further opportunity to re-examine the research questions and reflect on the priorities of the research
Training a researcher in as many elements of the research process as possible.	Achieved. This has been an opportunity to hone the researcher's skills of data collection and aspects of analysis. This will continue in the main study
Convincing funding bodies that the research team is competent and knowledgeable	Not applicable
Convincing other stakeholders that the main study is worth supporting	This was used to support progression into the final part of DHRes programme.

3.7 Phases of the Study

To conduct the study with a sequential approach to the data collection, two phases were planned as follows:

- Phase 1: On contacting the carers those willing to participate were asked to complete the initial self-administered questionnaire that ascertained socio-demographic data and to undertake a self-assessment using the COPE index (Balducci et al., 2008). Participants were asked at this stage if they would be willing to take part in the next phase of the study.
- Phase 2: On selection into the study a visit to the carer to obtain carer consent and the ego-centric network data was collected either in a face to face or telephone interview. Instructions were then given to complete the diary with return by post using a sae provided or by email if an electronic version was preferred. On receipt, the ego-centric and diary data was collated and used to guide the second meeting when the semi-structured interviews took place.

3.7.1 Recruitment and Sampling

It was recognised that when trying to recruit from elderly populations there can be particular difficulties recruiting within this group (Feldman, Radermacher, Browning, Bird, & Thomas, 2008; Groger, Mayberry, & Straker, 1999) and the problems associated with accessing 'hard to reach' groups are also well documented (Atkinson & Flint, 2001; Faugier & Sargeant, 1997). Flexible and innovative approaches were needed in order to maximise the numbers and diversity of potential recruits and therefore both direct and indirect methods of recruitment were used (Charlesworth et al., 2011). To facilitate recruitment Parkinson's UK was contacted once University ethical approval had been granted. A detailed application requesting their support was sent with full information on the study. This led to direct approval from Parkinson's UK to access local groups and key individuals in the organisation (see Appendix 9). Details of the study were also published on the Parkinson's UK website. Posters and participant information leaflets were sent to local groups for distribution amongst their members. Direct methods included the use of fliers, leaflets, and posters. These were targeted at unpaid carers looking currently caring for somebody. Fliers were distributed

through key gatekeepers, principally through Information and Support Workers (ISWs) employed by the organisation and at Parkinson's UK events and meetings. I attended and presented the study at six local group meetings, one carers' specific meeting and at one Parkinson's focussed dance group. The resultant participants lived in either a large metropolitan location or within the Home Counties. Although thirty informal carers were interested in the study, six decided not to proceed and four had demographics that were similar to others already selected. These four participants were informed by letter and thanked for their interest. Therefore, 20 carers were finally selected as participants.

3.7.2 Gatekeepers

Indirect means of recruitment was achieved by utilising gatekeepers and snowballing techniques. Individuals involved in managing and organising the local groups were approached and asked to identify potential recruits. Gatekeepers were given fliers, information sheets and posters for distribution. However, it was important to consider the role and motivation of the gatekeeper since there is a potential for bias and restricted access at this stage of recruitment. This has been clearly documented in a study involving carers and care recipients (Groger et al., 1999). In this study gatekeeper were particularly helpful. Four participants were directly recruited via the gatekeeper and three gatekeepers were particularly helpful in directing me to events and other Parkinson-associated groups and activities that led to further recruits. All were willing to share fliers and other material related to the study with carers they were in contact with and through their associated groups. Snowballing can facilitate access to concealed or 'hard to reach' groups (Atkinson & Flint, 2001; Faugier & Sargeant, 1997). In qualitative and descriptive studies described as ascendant research by van Meter (1990) this offers practical and pragmatic advantages (Hendricks et al., 1992). Recruits were asked for the name of another subject, who potentially could provide the name of another, and so on (Vogt, 2005). However, no recruits did ultimately share others' details. Given the nature of this study, a note was made of the inter-connections between participants that became evident during the study since this could potentially lead to an over-emphasis on the cohesiveness of the social networks under examination with 'isolates' continuing to be missed (van Meter, 1990). However, this also became useful in identifying key alters who 'bridged' groups and enabled the

transmission of information (Granovetter, 1973) and therefore added some supplementary data for the analysis. On receiving confirmation from a recruit that they would like to be involved with the study, preliminary contact was made. For several this was directly face to face at the Parkinson's UK meetings and for others this was by telephone. Arrangements were then made to complete the initial questionnaire. Depending on the situation the respondent would be given the flexibility to do this by post (a stamp addressed envelope was made available), over the telephone or face to face. As I entered this world of TSOs and particularly those groups associated with Parkinson's UK and other PD related activities, I too became a fleeting network member who was kindly given access through the contacts I made. This included snowballing activities with the carers and introductions via gatekeepers (the 'go to' people, network bridges and Information and Support Workers, ISW).

3.7.3 Selecting Recruits for Phase Two of the Study

Within this phase, two approaches were utilised to select 20 recruits for inclusion in the main study. Examining the emerging social networks through the diaries and semi-structured interviews with the network analysis supported on-going selection. The first approach involved selective sampling and, as the study proceeded, theoretical sampling was used to particularly increase the participation of male carers. These approaches to sampling were undertaken to enable the generation of rich information and a deeper understanding (Patton, 1990; Thompson, 1999). In qualitative research the purpose of the sampling is to identify those who possess particular characteristics that are relevant to the research (Barbour, 2014). Initial selection was achieved by using stratified purposeful sampling based on pre-determined criteria (Sandelowski, 2000). This was ascertained from the questionnaire the respondents had previously completed. Therefore, it was not ad-hoc but pre-conceived since it was based on a reasonable set of criteria informed by the literature on carers and social networks.

A matrix was developed (see Table 7) using the criteria that are viewed as significant in the caring role and care trajectory (Balducci et al., 2008; Beesley, 2006; Hirst, 2004; Pickard, 2010; Yeandle & Wigfield, 2011). The criteria included gender; cohabitation status; carer 'coping' index and hours of caring per week, the relationship of the carer to the individual and months of caring. This resulted in several sampling cells. These pre-specified combinations of variables alongside their 'confluence' (Sandelowski,

Table 7: The Sampling Framework

Carer characteristics		Sex		Cohabitation		COPE Index			Relationship			Hours of Caring/Week		Months of Caring	
		Male	Female	Yes	No	Negative Impact >15	Positive Value <11	Quality of Support <7	Partner	Kin	Other	<20	>20	<24	>24
Sex	Male	8		8	0	4	2	3	8	0	0	1	7	0	8
	Female		12	9	3	4	2	1	9	3	0	1	11	2	10

Table 8: Sampling Strategies (Patton, 1990)

Sampling Strategy Preliminary Approaches	Use in this Study
Snowball sampling: Identifying cases of interest from respondents and 'gatekeepers'	Gatekeepers were helpful in identifying more male carers
Criterion case sampling	Picking cases from initial respondents that met pre-determined criteria
Maximum variation sampling	Selecting participants from initial respondents to increase variation on the dimensions of interest
Sampling Strategy Later Approaches	Use in this Study
Intensity Sampling	Examined information rich cases which included detailed interviews or rich diary data
Extreme or deviant case	Examine unusual cases. Of note was the case where private healthcare was extensive and the carer who was a single adult daughter with no other family support
Typical Case Sampling: To illustrate or highlight what is typical or normal.	The majority of the participant carers were female
Stratified Purposeful Sampling: To illustrate characteristics of particular subgroups and facilitate comparisons	The number of years caring and the hours spent caring each week were also included to expand on key characteristics
Theory based. To examine a theoretical construct of interest, allowing elaboration	Recruited from a particular 'dance' group that was unique and offered an insight into 'the strength of weak ties'
Opportunistic or emergent sampling. Follow new leads-enhances flexibility	Recruited from a particular 'dance' group that was unique and offered an insight into 'the strength of weak ties' Carers with and without children and with stepchildren were included. Migrants were also included.

2000) aided closer examination of how social networks operate in such cases. Decisions related to recruitment and sampling were therefore determined by the sociological perspective underlying the research question and therefore required identification of the population and setting being studied (Draucker et al., 2007). As the study progressed two areas of recruitment proved to be more difficult. This included male carers and non-kin carers. As discussed previously, 'gatekeepers' were extremely helpful in facilitating contact with male carers that they were aware of. This resulted in the recruitment of a further four male carers towards the end of the data collection period. All the males recruited were married to the care-recipient. No male, adult children came forward as potential recruits. Also, it did not prove possible in the timeframes available to recruit any non-kin carers, although one male friend of a care recipient expressed interest, he did not respond to the follow up contact.

Selective sampling allowed for theory development (Thompson, 1999), as categories emerged from the data collection and analysis. (Coyne, 1997; Draucker et al., 2007; Strauss & Corbin, 1990). Comparing the data across cases ensured that emerging categories were tested against the incoming data (Coyne, 1997). Iterative changes were required to alter aspects of the data collection as categories emerged and are refined in this recursive process of data collection and analysis. Data collection amendments included slight alterations to the interview schedule, checking or collecting more data from existing participants or new participants, or returning to the literature. Patton (1990) has identified 14 sampling strategies that can be appropriate to utilise. Table 8 outlines some of Patton's sampling strategies that were used either initially or later as the data was analysed.

3.8 A Personal Perspective on My Research Journey

It is important that I reflect on my research journey and consider my positionality in terms of my individual perspective and approach to this research (Savin-Baden & Howell, 2013). This influenced the reasons for choosing the topic area, how the research was conducted and consequently the interpretation of outcomes and findings (Rowe, 2014). Throughout the work it was important to be reflexive, that is, to be self-conscious, with personal analysis and scrutiny of how my own experiences influenced

my study. Reflexivity enables a researcher to understand that they are integral to and integrated within the research (Savin-Baden & Howell, 2013). Therefore, critical consideration of personal standpoints within the context of the methodology and the conduct of the research should be articulated (Savin-Baden, 2004). Throughout the study, records and notes were maintained that included reflections and commentary on many aspects of the research. Reflective practice was a skill I had honed as a nurse and educationalist throughout my professional career. Using a reflective diary aided critical thinking and my decision-making processes throughout the study (Schön, 1995).

Choosing the Topic Area

My interest in the study focus originates from professional and personal perspectives. As a Registered Nurse working predominantly within in-patient medical units, I dealt with many carers who were supporting kin (or sometimes friends) with difficult long-term medical conditions. The nature of the illness, and for some, repeated hospital admissions, meant that the patients and their carers would become well-known to the ward teams. As I became a more experienced practitioner, I was conscious of the importance of developing a good relationship with the carers since their expertise and unique understanding of the patient and their condition could really facilitate and enable the decisions that were needed to deliver the most appropriate care. Over time I recognised the significance of their role and, with some, had glimpses or snapshots of the care trajectory as the illness progressed and there were repeated hospital admissions. It was evident that these carers, in their role, were often taking the strain from the health service and it could be both emotionally and physically difficult for them. The group of patients I nursed also included those with PD. For this group, their admission would often be related to a crisis, to manage quickly progressing disease or when the disease was seriously impacting on their physical and/or cognitive functioning. The medical presentation of this group was usually complex and multifactorial with the presence of other co-morbidities associated with ageing. Even in a medical setting the range and complexity of the drug regimens was often remarked upon, and the team had to be vigilant to effectively manage this aspect of care.

Personally, I also saw, first-hand, my Mother care for her partner over a ten year period, from his diagnosis with PD until his death. During this time, they joined a local Parkinson's UK group to gain information and support. For a few years before the PD became too debilitating, they enjoyed outings and meetings, making new friends, and actively contributing to their local group. Throughout her life my Mother struggled with relationships, and yet she appeared to integrate with the people in this group, finding their support and friendship valuable. Given her previous relationship difficulties I often reflected on what it was about the group that enabled her to form these friendships. Her involvement with this sector also made me consider TSOs as a further avenue and adjunct to support separate to the formal care sector. These observations gave me a broader interest in informal carers, their experiences of the role and their wider position within society. Thus, I became interested in carers' networks of support and how they access and build their networks to aid their role. I envisaged that greater understanding of this could improve the assessment of carers' needs and help to improve the design and delivery of services.

Conducting the Research and Positionality

Early in the design of the project, I had to grapple with the methodological approach that I was going to take to research this area. My previous academic work was based in the biosciences and clearly within a positivist paradigm. Initially I was drawn to undertaking a study with large numbers of participants that would concentrate solely on quantitative and mathematical approaches to social network analysis. However, as I began to consider the participants, the aims of this work and the potential research questions, it became apparent that this would only give a partial understanding and explanations about the interactions and processes that take place within the carers' networks of support. Considering previous studies that described or considered qualitative approaches in relation to exploring individual's networks, the nature of supportive relationships and/or the concept of social capital (for example; Bott, 1955; Hollstein, 2011; Finch, 1989; Finch and Mason, 1993; Phillipson et al., 2001; Boneham & Sixsmith, 2006; Campbell & McLean, 2002; Cattell, 2001; Dolan, 2007), it became apparent that an interpretive paradigm using a constructivist approach would more clearly represent the interactions and processes that occurred in these networks and the findings would reflect the cultural, social and historical context (Creswell, 2009). See section 3.2 for a more detailed discussion on the constructivist approach.

When considering my research design, it was vital to acknowledge my position in relation to the participants and how this might influence the research process in terms of the carers perception of me and how I collected and interpreted the data (Holmes, 2020). Thus, my role as a nurse, researcher, educationalist and increasingly, as the study progressed, a distant carer of my own Mother, all had an impact on my approach. My personal and professional roles offered an emic or insider perspective as a carer myself and from my role as a nurse observing the carers in their role while I was working in practice. However, as somebody who was in the capacity as a researcher, I was conscious that there may be some uncertainty about how the carers might view my position. On first meeting the participants I explained my various roles, disclosing my previous professional work with carers, my observations of my Mother in her role and then my role as a carer for her. To clarify the boundaries of my position, I was clear at each interview about my current role as a researcher, not as a health professional (Mason, 2002). Despite this I was still approached for advice about medication at interview and although I ensured that the carer had time to discuss their concerns, I directed them to their GP, hospital Consultant and PD nurse. There are commonalities in approach, in respect that both health professionals and researchers require a code of ethical practice that aims to ensure the well-being of patients or participants (Easter et al., 2006).

There was a balance to maintain between the insider (emic) position and outsider (etic) perspective as I formed my relationships and, through a constructivist approach, using my tacit (emic) knowledge sought to derive a co-constructed meaning of their social networks. However, I also needed to consider my position as an outsider knowing that I might not truly understand their personal, social, and biographical context. There are arguments for both positions, with the insider perspective offering a real understanding of the participants, whereas the outsider is more able to detach from the situation limiting bias (Kusow, 2003). Personally, and as described by Herod (1999), I found that a true duality in this respect did not exist, but there was a continuum with nuanced interactions and social processes occurring between myself and the participants at each encounter of the data collection. These interactions ultimately shaped the process and the data obtained.

I feel I developed a good rapport with the participants as was evidenced in the overall data obtained. However, after each meeting or encounter I sought to reflect on my

subjective thoughts and emotional reactions to their situation (Henn et al., 2006; Kingdon, 2005). I was conscious that my insider status as a woman with the wives and daughters in the group probably enabled a greater openness and ease of discussion than with some of the male participants. Feminist studies where women have interviewed other women have commented that such an insider status can engender trust and openness (Finch, 1984; Oakley, 1993). My emotional reactions to the carers and their situation varied across the participants. I felt a particular empathy with Mary who, like myself, was an only-child caring for her mother. For those who were immigrants (a situation I had never experienced), I had to contemplate and carefully analyse the impact of this on their networks and their role. In respect of Elizabeth's situation, it was unique, and having worked in the NHS and public sector throughout my career, her network and the extent of private healthcare involvement was a revelation to me. Again, at data analysis, careful consideration of the context of this extensive provision and its place in the network of support was needed to reflect its meaning and significance to this carer.

In reflecting on my data, I was struck by the dynamism of the networks that I was examining and how this also shaped my entry and access to different individuals across the network. These excerpts were gathered early in the data collection period, although the interviews were six months apart. When I recognised Mary's account from my earlier interview with Carly, I suddenly grasped the power of the dynamics in the network and how this sustained and propagated the network itself. This was a real insight an 'aha' moment. As the study continued, other examples of sharing leading to a diffusion of information through the network as connections developed was clearly evident. For several carers, entry into a TSO such as a Voluntary or Community Organisation led on to other groups and opportunities with introductions and exposure to a wide range of contacts.

Mary recounted another introduction (through the main Parkinson's UK group) that opened the door to her mother and herself joining the ballet group.

JS: *How did you get involved with the [named dance group]?.....Was it with [named Parkinson's group] or was it through meeting Joan that you went to the ballet? How did that work for you...?*

Mary: *Well that...the [named dance group] actually happened because the [named dance group] came to the Parkinson's meeting...*

JS: *To the group, right ok, to tell you about it right...*

Mary:: *Yeah they obviously wanted people to get involved...*

JS:: *You must, so were you in the first group then really, were you, you were one of the first members...*

Mary: *Yeah, there from the beginning*

At the time of meeting Mary, she had been involved with the Parkinson's UK group for approximately five years. As we discussed her involvement in the group and the wider carer network it became apparent that she too had become a bridging tie and was now opening doors for others. At one point after discussing some of her own fears and difficulties in caring for her mother with her GP, Mary was referred to a carer support session. It was at this support session that she met Carly. She explained this meeting to me and how she had recommended the [named dance group].

Mary: *there was another lady there, who was on her own looking after her husband with Parkinson's and I, I, I always think that maybe my reason for going there was for her to meet me, for me to introduce her to [named dance group] because [now] she goes there with her husband and everything..... I said oh God you need to go...to this you know [dance group], this is what they doand I got her, gave her [ISW's] number and all different things you know about the [named dance group] and umm...I remember we went and had like a coffee after...one of the talks and stuff and umm...me giving her all this information and then seeing her at the [dance group] one day. It was just so lovely coz I kind of saw a different person, you know. Coz she kind of all of a sudden she kind of had people that...you know like, older carers like herself but also her husband was able to see that it was look, it's not all bad. You know there can be good things out of this, and look there's other people with the same thing but they've still got a sense of humour and stuff like that you know...*

My interview with Carly was sometime before I met Mary. This is the account in her interview about how she was informed about the dance group and was given the [ISWs] details

Carly: I was at [name of carer organisation] for a group with umm a couple of psychologists who were doing little short course...I mean it was a day for carers with depression and so the carers there weren't just for people with PD....It was for any, for caring with any disability and in the little break that we had with coffee I was chatting to the girl beside me ahh whose name was [Mary], and you know you both say...well who do you care for? Well her mother had PD and she said...oh my Mother's joined this wonderful dance class...and that was it, that's how I found out that was the start of something very special in our lives...

The Outcomes and the Findings

The decision to follow an interpretive paradigm and a constructivist approach utilising predominantly qualitative data was the right one. The diary-interview approach gave rich and detailed accounts that clearly illuminated the detail of the social interactions across these networks as the carers undertook their role. However, the social network name and role generator data was also a valuable tool in illustrating the carers' networks. This aided co-construction of the network at interview and offered reflexivity as the carers considered the shape and utility of their network structures. The use of fixed questions to generate the ego-centric network data offers a very prescribed and controlled method of collecting this data. On reflecting on my use of this approach. I think my early nervousness with qualitative data and the need to have a sense of control in the data collection process (a consequence of my prior biomedical research training) influenced this choice. Reflecting on the strengths of other approaches to generating a pictorial or participant-led depiction of a network structure (see Ryan et al., 2014 and Campbell et al., 2019) has allowed me to recognise that these approaches offer greater creativity, interaction, and participant control in their construction of the network. Now that I have greater confidence in my qualitative researching skills it is an approach I would consider in the future.

The study was distinct and unique in its focus on the networks of those who care for somebody with PD. Access to this group of carers via Parkinson's UK allowed me to

meet a very particular group of carers who were especially involved in the organisation. Thus, the data collected offered a very particular view of this 'space' (Evers, 1995) or field (Bourdieu & Wacquant, 1992) and uncovered a very particular aspect of support in the community. However, it must be acknowledged that this access was clearly directed through one organisation, and although the sampling was purposive, with efforts made throughout the data collection to incorporate a diverse range of individuals, there would be carers, who by virtue of not associating with Parkinson's UK, would not participate in this study. Thus, access to 'hidden' carers i.e., those who do not identify with the role or those who are out-with local community support structures or not-known to more formal health and social care services (Cavaye, 2006; Barnes, 2012; Carduff et al., 2014) could not be achieved. These carers will potentially have quite different support networks and there may be many contextual factors that shape these networks for this group. This indicates that further work is needed to examine the networks of such a group with a consideration on how these networks may differ when compared to those in this study.

3.9 Part 1 Summary

A case study methodology using qualitative approaches with network data was utilised to explore the forms, functions and associations of the carers' social networks. This allowed an exploration of how resources were leveraged through network interactions and their impact and effect on the caring role. Biographical details, the COPE index and social network analysis provided quantitative data that was complemented by qualitative data from participant diaries and semi-structured interviews. The diary-interview method (Zimmerman and Wieder, 1997) alongside visualisation of the diary data at interview offered a very valuable means of developing and exploring the data with the carer. The sequential approach (Creswell, 2009) taken by collecting the network data first followed by the qualitative data enabled these techniques to be employed. Thus, the various forms of data informed the case study and improved validity and reflexivity through triangulation and participant checking allowing the findings to be cross validated (Jupp, 2006).

3.10 Part 2: The Data Analysis

This section will discuss how the Framework Method of data analysis as originally devised by Ritchie and Spencer (1994) and more recently described by Spencer, Ritchie et al., (2014) was used to examine and analyse the data. The approaches undertaken needed to reflect and support the case study methodology and the approaches to data collection. The biographical data and quantitative data from the network analysis needed to be descriptively presented whereas the qualitative data from the diaries and interviews required more interpretive approaches to analyse the interview data thus capturing the detailed and rich descriptions of the carers' networks.

3.11 Using a Framework Approach to Analyse the Case Studies

Framework analysis was originally developed by Ritchie and Lewis (1994) to allow a manageable approach to ordering and examining the data and for subsequently analysing and interpreting the findings. The key elements to this approach are clearly described by Spencer et al. (2014) as follows:

- Familiarisation:
- Constructing an initial thematic framework
- Indexing and sorting
- Reviewing data extracts
- Data summary and display

In relation to this study each of these elements will be described and detailed in terms of the analytical approaches taken and the emergent findings and interpretations outlined. Appendix 10 also illustrates these stages using the data from the study.

3.11.1 Familiarisation with the Data

During this stage it was necessary to become immersed in the data. Given that the data was attained by different approaches, the various types of data including the biographical details of each carer, the scoring from the COPE index (Balducci et al., 2008), the name generator data with the associated sociograms, diary data and interviews were all carefully reviewed. Familiarisation with the various forms of the data for each carer was beneficial (Pope et al., 2000). This allowed each data element to be drawn together with the other components. This triangulation allowed integration of these components leading to a final perspective or ‘whole that became greater than the sum of the parts.’

All the name generator questions were initially scribed and then typed into word documents. From the name generator questions it was possible to generate ego-centric networks for the different questions posed by simple analysis using the UCINET software (Borgatti et al., 2009). The diary data was firstly tabulated to ascertain the number and range of individuals listed. For both the name generator and diary data a grid of role relationship and support provided (using Thoits, 2011) was used to facilitate within and cross-case analysis.

To ensure familiarisation with the interviews, each recording was listened to on three separate occasions. Notes and memos were made after the initial interview and on listening to the audio tapes. These were used as aide memoires on returning to a transcript. Each interview was then transcribed and then re-read several times. Further notes and memos were made at this point and sections were re-checked against the original recording if there appeared to be errors in the transcription. For each carer a summary document was then prepared that captured key elements of their data. The qualitative data analysis software NVivo™ 11 was used to store and analyse the qualitative data

3.11.2 Constructing the Initial Thematic Framework from the Data

In approaching this aspect of the analysis, several concurrent and iterative processes were employed. It was evident that there was a large amount of data that needed to be organized and ordered. Initially each case formed a holistic unit of analysis, thus

the data collected for each participant was collated, prepared, and analysed for each carer. To determine the initial preliminary framework a three-stage approach was utilised.

Stage 1: Returning to the theoretical perspectives and the research objectives.

The original research questions were as follows:

- What are the forms, functions, and associations of carers' social networks?
- How do carers access and utilise the resources contained within these networks?
- How do their social networks impact on their caring role?
- What role do the health and social care sectors and the local community in shaping or developing carers' social networks?

The biographical data, COPE Index and quantitative data generated in relation to the network analysis became a key thematic area, termed 'Background.' However, in considering how to further approach the analysis it was evident that the key structural components of each carer's network would form further key themes. The associated interactions and processes associated within each part of the network were then delineated to form sub-themes. Given the approaches that had been used, the quantitative data would delineate the form and size of the networks, whereas the qualitative data would elaborate on the nature of the carer's relationships and their impact on the caring role.

Stage 2: Identifying the structural components of the carer's network

Theoretical models were used Each theoretical perspective or 'lens' alongside the methodological approach utilised were reconsidered as the data was examined and analysed. This included:

- Cantor's (1979, 1991) Model of Social Care and Kahn and Antonucci's Convoys of Social Support (Antonucci, 1985; Antonucci et al., 2009; Kahn & Antonucci, 1980)
- Social Network Analysis

- Social Capital

Both Cantor's Social Care Model and Kahn and Antonucci's Convoy Model offered a structural and 'convoy' perspective to consider the differing support components that formed the carers' social network. Cantor's (1991) model (see Figure 1) envisaged the elderly requiring support and at the centre of a range of enveloping structures which included formal and informal elements. The central support is viewed as informal and consisting of family, friends, and neighbours. Moving from the centre to the periphery, the support becomes more formalised and finally includes political and governmental organisations and is hierarchical in its structure. The elements of the model exist side by side and offer different forms of support within a variety of settings and contexts. There is a 'fluidity and overlap' (Cantor, 1991 p.339) of each component and the boundaries are affected by changing demographics, legislation, economics, and societal change.

The convoy model also recognises the giving of care as being situated in a system that consists of networked individuals (the 'convoy'). However, this has a more dynamic and fluid property, since it recognises that the network can evolve and morph over time. In both models, social ties, and the ensuing relations and how care is provided are central tenets. Utilising social network analysis enabled a detailed picture of each carer's network of support to be uncovered and gave a detailed structural picture of an individual's network. For this study, when analysing the data, the carer was viewed as the central component in the network structure. Hence, this perspective offered a means of examining the structural or network elements that surrounded the carer and were unique to them in their caring role. Although the study examined the role of family, friends, neighbours, and other acquaintances a further key objective was to examine the intersection between the carer and those networks formally developed through interaction with health and social care services alongside those more formally or informally developed through TSOs (including voluntary and community organisations). In examining the data recognising the overlap and interaction between each aspect was also important since it helped to illuminate those connections in the system between informal, semi/quasi-formal and formal components.

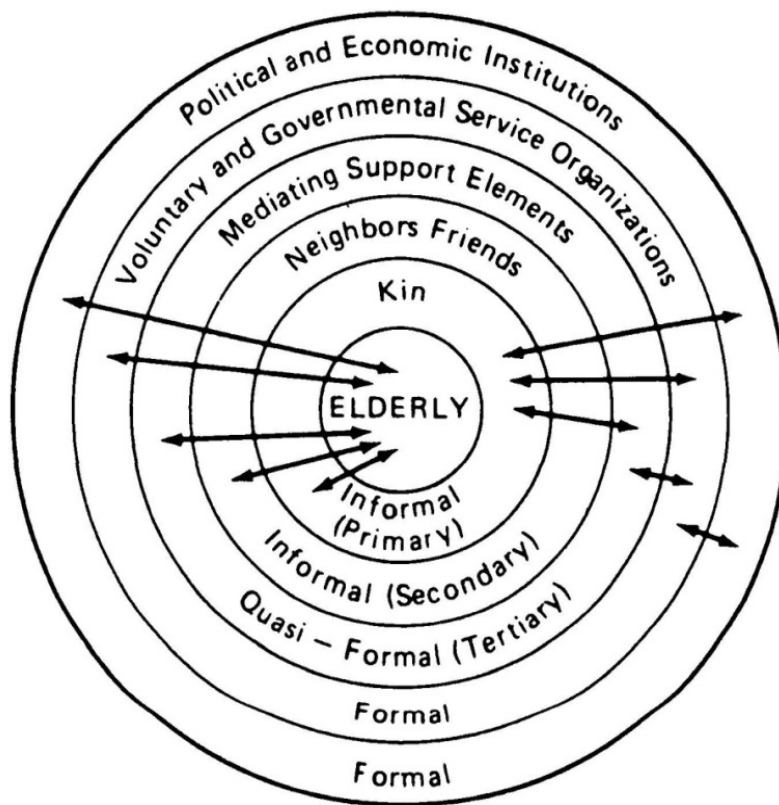


Figure 1: Cantor's (1991) Social Care Model

Preliminary survey data for the initial responses was handled using simple descriptive statistical methods. The UCINET computer programme (Borgatti et al., 2009) aided initial analysis of the diagrammatic network data. This was then combined with the qualitative approaches. As such the structure and the context of each carer's network could be visualised, examined, and understood.

Stage 3: Identifying the functional aspects of the network: processes and interactions

Both Cantor's Social Care Model (1979, 1991) and Kahn and Antonucci's Convoy Model (1980) acknowledge that in terms of the interplay between each component or alters there are a range of dynamic interactions and processes that take place to provide support and care. Therefore, in the analysis the various 'acts, practices, interactions and communications' (Hollstein, 2011 p.406) that occurred within and between each of the structural elements was closely evaluated. Illumination of these

intricate processes was therefore possible in the unique context of the carers' social networks (Field, 2008; Prell, 2012).

However, the concept of social capital also offered a further theoretical lens to examine not only the structure of the social networks but also the exchanges (in terms of affective and other more tangible resources) within those social relationships that may or may not be providing support to the carer in their caring role (Peek & Lin, 1999). Examining and understanding the nature of the transactions that took place in the carers' networks offered useful insights, particularly in those processes that occur in relation to the caring role (such as discussions and exchanges of resources, information, and advice) (Perry and Pescosolido, 2010) and the benefits or outcomes of such exchanges (Dominguez & Watkins, 2003). Thus, the network structure and the social support or other potentially negative effects arising from this could also be conceptualised through a social capital lens.

In examining the data, the three functional forms of social capital were considered, i.e., bonding, bridging, and linking social capital. The definitions previously discussed in the literature review are summarised below:

- Bonding social capital: characterised by strong bonds, examples might include, networks within a family or among members of an ethnic group; often associated with personal support and close friendships (Ferlander, 2007).
- Bridging social capital: associated with weaker network ties that span or cross individuals of differing, age, race, social class etc. and as such it is viewed as more inclusive in nature; facilitating the sharing and exchange of information through diverse social networks (Granovetter, 1973, 1983).
- Linking social capital: those networks that connect individuals in society that are in different hierarchical positions (Szreter & Woolcock, 2004). The concept of linking social capital was therefore particularly considered when analysing the data that related to the health and social care element of the network and the practices and interactions that occurred there.

Therefore, once it was determined that the key themes should follow those social structures that surrounded the carer a further process of delineating those functional aspects through the qualitative analysis of the diary and interview data then took place.

Although Richie and Lewis (1994) do not describe 'coding' per se, within this process it was decided to stay very close to the data, initial coding would be used. This allowed me to refine and develop my researching and analytical skills with qualitative forms of data. The computer package NVivo™ 11 was used to aid the qualitative data handling in this respect. Following Charmaz (2006) in the early stages of analysis, segments of data were examined. This resulted in the generation of many codes. With time it became possible to keep the 'codes simple and precise' and 'move quickly through the data' (Charmaz, 2006, p.49). Data comparisons were undertaken across the cases as the analysis continued. Using notes and memos throughout the study acted as an aide memoire, they were also important tools in capturing thoughts and ideas as the study progressed and facilitated linking of data (Hughes, 1994; Orona, 1990). Interim summaries also captured the data and evolving analytical outcomes at key points in the process and were helpful in displaying the data (Robson, 2002). Coding of the data enabled detailed descriptions of the participants within their own unique contexts and facilitated the formulation of categories and themes that were supported by the data (Creswell, 2009).

These open codes were then re-examined considering the original research questions and several initial sub-thematic or index headings (Ritchie et al, 2014) were then developed under each main thematic heading of the different structural components of the carer's network. To undertake this thematic approach the codes were ordered into patterns and clustered where there appeared to be a commonality of meaning or link to a key social process or interaction (Braun & Clarke, 2013). These qualitative approaches therefore enhanced the understanding of the form, functions, and associations of the networks. The access and use of resources in the networks, including emotional, instrumental, and informational support and companionship could also be explored and evaluated (Ferlander, 2007; Granovetter, 1973, 1983; Thoits, 2011; Vassilev et al., 2011). For each participant (or case) their data was organised individually to address the original research questions that were guided by the theory on social capital and social networks. Such a theoretical orientation aided the organisation and analytical approaches. This analysis of the qualitative interview and diary data with the network data and the initial biographical data allowed for a fully integrated approach facilitating a fuller depiction of the carers' networks.

Thus, during familiarisation both *a priori* categories were identified informed by the objectives of this study and other categories arose from the participants' own view and articulation of the function of their networks in relation to their caring role. Using analytical logic allowed codes and themes to be formulated and constructed for each case (Mason, 2002) and then across cases. As such for each participant it was possible to explore the nature of their social networks and identify their utility in the caring role. This helped to uncover and examine explanations derived from each participant (case). As the analysis progressed it was then possible to comparatively analyse these across the cases. Over time these processes then occurred in tandem (Mason, 2002). A diagrammatic representation of this can be seen in Appendix 11. The thematic framework evolved and was iterative initially. Once determined it was applied to enable the indexing and sorting of the data.

3.11.3 Indexing and Sorting / Reviewing Data Extracts

Undertaking on-going analysis with each case allowed the data to be labelled accordingly under the heading of the initial overarching structural themes and the sub-themes within those. Within each theme further analysis then began to sort each area in turn. This allowed the 'detail and distinctions that lie within' for each case and across cases to be viewed (Ritchie et al., 2014 p.303). This ensured that the themes were meaningful and distinct. On-going analysis allowed themes to be refined, defined, and named. Utilising NVivo™ 11 it was possible to review individual themes by case and across cases. This allowed for further analytical examination, re-ordering and categorising of themes that then led to data summary.

3.11.4 Data Summary and Display of the Data using Framework

Data summary and display was possible with NVivo™ 11, however Microsoft™ Word was also used to create tables for analysis and comparison of the cases. This was used as part of the analytical process. The tabulation of the data for each case within each theme/sub themes facilitated the representation of the data for that case. The data that emerged could then be compared and analysed across the different cases. This display allowed verification of the data and was also necessary to test and confirm the findings (Robson, 2002). The use of the framework aided an on-going iterative

process of refinement of the coding categories and themes further aiding data reduction (Miles & Huberman, 1994).

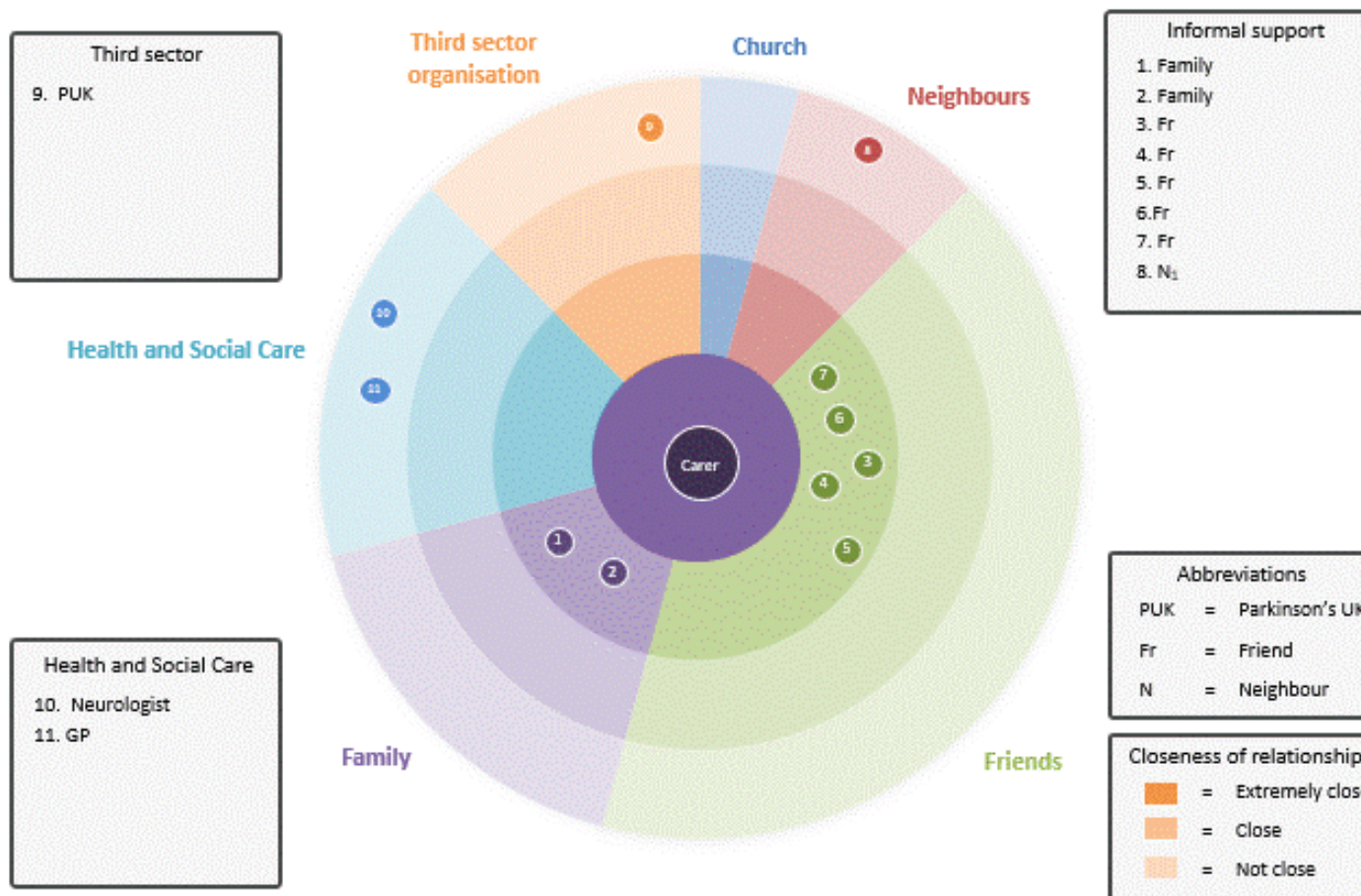
3.11.5 Abstraction and Interpretation of the Data

At this point, data display in the matrices led to data reduction as key dimensions within each main theme became evident. In this interpretive phase, inductive concepts/themes were generated from the data that offered explanations from across the data.

3.11.6 Visual Techniques and Representation of the Egocentric Data

By using the network generator data from all the questions and building on the original simply structured, and unstandardised egocentric maps (used with the carers as an additional narrative aid during the data collection, (see section 3.4.7 and Appendix 5 for an example), a number of detailed egocentric maps were developed that captured significant elements within the carer' networks. These were based on a hybrid structured and unstandardised approach (Hollstein et al; 2020). Structurally the data is presented in concentric circles as described by Antonucci (1985) and relationships to the alter are included in sectors. This offered a structured approach to network mapping. However, to fully illustrate all elements for each participant the naming of the sectors had some individual variations and were directed by the carers' data, thus also offering a non-standardised approach. Using named sectors particularly across the informal structures in the network also further illustrated some of the more nuanced detail. The use of Excel™ and quantifying the size of the sector components via a pie chart design also illustrated the size and significance of alters or groups within the informal and formal networks. See Figure 2 for a generalised schema of the sociograms that were produced. This approach allowed for comparisons across the participants. Within the discussion of the results (chapter 5, 6 and 7) the carers' egocentric maps will be presented to illustrate the findings.

Figure 2: A Generalised Egocentric Map Produced for this Study



3.12 Maintaining Rigour in Analysing the Data and Presenting the Findings

In considering the design of this research critical consideration was given to the nature of the methodology that enabled a credible approach to the research questions. However further consideration was also needed in relation to the rigour used in the production of the findings of the study. This relates to issues of reliability, validity and generalisability (Creswell, 2009). Reliability was maintained by checking the accuracy of the transcripts and care in determining codes with constant comparison of the data through the course of data collection. Several approaches were used to maintain validity, including triangulation; participant checking of the findings; examining bias through reflection and reflexivity; presentation of discordant information and supervisory peer debriefing (Creswell, 2009; Mason, 2002). Using several data collection tools assisted triangulation. Patton (1999) outlines 4 methods of triangulation as follows:

- Method Triangulation

It is possible to assess the consistency of findings generated by the different methods. For example, it has been found that diary data is more reliable when compared to interview data but is less reliable when compared to logged telephone conversations (Conrath et al., 1985). Triangulation of sources was undertaken for each method, and the consistency of the different data sources across the methods of data collection were considered.

- Analyst Triangulation

The supervisory relationship supported this aspect as ideas and thoughts were discussed in relation to the data and the existing research and theoretical approaches.

- Theory or Perspective Triangulation

This was achieved by revisiting the various theoretical perspectives of social capital and social network theory.

- Participant or Member Checking

The involvement of participants in producing their diaries and ego-centric data and then returning to this data during the semi-structured interviews offered a real and genuine opportunity for 'member checking' (Creswell, 2009, p. 191). The diary-interview method offered a clear opportunity to check the internal consistency of participants' accounts from their diaries, and highlighted omissions whilst allowing greater exploration of the pertinent issues (Zimmerman & Wieder, 1977). Sharing and discussing the accuracy of these aspects of the study also allowed participants to comment and aid validity. It is important to clarify researcher bias. Reflexivity requires articulation and critical consideration of personal standpoints within the context of the methodology and the conduct of the research (Savin-Baden, 2004). Detailed records and notes that include reflections throughout the process were used to allow transparency and critical thinking (Schon, 1995).

Discordant information and negative cases were included and discussed in the context of the findings. Such cases needed to be carefully examined in terms of the theoretical constructs underpinning the work since deviant cases test the theory and may lead to theory modification (Mason, 2002; Silverman, 2005). Mary and Caroline were unique typologies, in comparison to others in the study, that were identified and examining and comparing their individual cases to others allowed a fuller understanding of how a 'Personal Community' is constructed. These cases acutely illustrated how historical contexts and life-course trajectories impact on the form and function of the networks that surround carers. In terms of generalisability, it was important to consider the original research questions, the research design sampling and processes undertaken (Mason, 2002). In qualitative research the aim is not to generalise empirically but to generalise in the context of the theoretical frameworks that have guided and underpinned the study. For this study, an understanding of the carers' unique networks and the overall context of those networks was key to elucidating how these were constructed and maintained. In this case any generalisations will relate to the constructive nature of the knowledge created within the context of the work, and in relation to social network and social capital theory, and the theoretical models considered (Gomm et al., 2000; Kvale & Brinkmann, 2009).

Finally, to summarise the methodological approach and data analysis from this case study design Eisenhardt's (1989) process of building theory from case study design is presented. See Table 9.

3.13 Part 2 Summary

The Framework Method of data analysis (Ritchie and Spencer, 1994; Spencer et al., 2014) offered a rigorous and stepwise approach to the analysis of the data that was collected. Both Cantor's Social Care Model (1979; 1991) and Kahn and Antonucci's Convoy Model (1980) were utilised to offer a structural and 'convoy' perspective when analysing the components that formed the carers' social network. By incorporating the Cope Index (Balducci et al., 2008; McKee et al., 2003) and social network data with the qualitative diary entries and interview transcripts, both the structural aspects of the network and the complex series of inter-personal exchanges that took place in the network, were combined giving a full and comprehensive picture of the carers network of support. From these the positive and negative impacts of the network on the carer in terms of their caring role were elucidated. Therefore, analysis and understanding of this social phenomenon and the complex interactions of the individual within their own personal community and more widely with other semi-formal and formal structures became apparent. These findings also demonstrated the dynamism of the system with processes within each structural element influencing and shaping other areas across the informal and formal sectors of care. Finally, those political and economic institutions that enable and direct support and care through Government legislation and the provision of services were also highlighted.

Table 9: The Process of Theory Building from Case Study Research adapted from Eisenhardt, (1989)

Step	Activity	Summary of this Study
Getting started	<p>Research objectives</p> <p>A priori constructs</p>	<p>To examine the forms functions and associations of carers' social networks and their utility in the caring role. Review key objectives/ key questions of the study</p> <p>Cantor's Social Care Model; Kahn and Antonucci's, Convoy Model. Social Capital, Social Network Analysis</p> <p>Current health and social care policy. Carer position in society</p>
Selecting Cases	<p>Select population</p> <p>Sampling: Purposive and snowballing; theoretical not random</p>	<p>Utilising the literature to determine theoretical sampling</p> <p>Carers accessed via Parkinson's UK</p> <p>Accessing seven local groups and a Parkinson's dance group</p> <p>Access and support were extremely helpful and facilitative. The researcher as a member of the network. Seeing the network in action.</p>
Crafting Instruments and Protocols	<p>Varied data collection</p>	<p>Biographical –proforma; COPE Index; Name generator questionnaire, Diary design and interview questions</p> <p>Pilot Study</p>
Entering the Field	<p>Carer contact and negotiation</p>	<p>Diagrams offer an insight in to key alters and their role in the network</p> <p>Diary-invaluable for expanding the SNA data and capturing 'snapshots in time'</p> <p>Reflexivity when discussing the observed network during the interview</p> <p>Interview offered an opportunity to expand/ look in- depth-consider temporal aspects</p> <p>Meeting participants-social interaction, norms of behaviour/, researcher role</p> <p>Shaping of the study through the participants' networks-reflexive action in action</p>

Table 9: (continued) The Process of Theory Building from Case Study Research adapted from Eisenhardt, (1989)

Step	Activity	Summary of this Study
Analysing Data- Shaping Theories and Constructs	Within case analysis and across case analysis	Returning to the original questions: Keeping observational and theoretical memos Returning to a <i>priori</i> constructs/ Coding and thematic analysis within cases. Developing a thematic index based on structural and functional components Comparative analysis across the cases using a Framework Approach Key aspects: The Network Typologies The Carer's Personal Community- Key alters; relationship and dynamics. Bonding social capital Third Sector Organisations: evidence of bonding and linking Health and Social Care; Evidence of bridging and linking social capital. Other mediating social structures
Enfolding Literature	Comparison with similar/conflicting literature	Returning to the literature to examine the findings and to critically analyse the outcomes of this work
Reaching Closure	Theoretical Saturation	Finalising the conceptual framework and synthesising the data

Chapter 4: Introducing the Participants

4.1 An Introduction to the Carers

Utilising the data obtained from the participant pro-forma the key demographic details of the participants are described. This is also supplemented by the network generator data. In Appendix 12 there is also a brief background to each of the twenty participants. All names are pseudonyms.

4.1.1 Profile of the Carers and the Care Recipient Relationship

The summary profile of each carer is given in Table 10. Of the 20 carers that were recruited 12 were female. Seventeen of the carers were co-habiting spouses. Partners predominated in being the main carer for the care recipient. The remaining three carers were adult daughters one caring for her mother, the others caring for their fathers.

4.1.2 Age Range, Overall Hours and Months of Caring

The age range of the carers was 47—80 years. In this study 15 were aged 65 and over. The hours of caring ranged from less than 20 hours up to the maximum of 168 hours (i.e., around the clock). Twelve of the participants (all spouses) aged over 65 were providing over 50 hours of care per week. Over 50 hours per week is viewed as intensive and is often associated with greater carer burden and poorer carer health with eight of those providing over 100 hours per week (Pickard et al., 2016).

Table 10: The Carers' Demographics

Case	Relationship to Care Recipient	Carer Assessment	Age	Sex	Occupation	Health	Hours of Caring per Week	Months of Caring	COPE INDEX		
									Negative Impact >15	Positive Value <11	Quality of Support <7
Carly	Spouse	No	62	Female	Retired	Fair	133	144	>15	NA	NA
Cilla	Spouse	No	74	Female	Retired	Fair	165	240	NA	NA	NA
Mary	Child	No	47	Female	Student	Poor	35	84	>15	<11	<7
Elizabeth	Spouse	No	66	Female	Retired	Very good	100	72	NA	NA	NA
Julia	Spouse	No	75	Female	Retired	Fair	24	36	NA	NA	NA
Harriet	Spouse	No	73	Female	Retired	Fair	2	24	NA	NA	NA
Margaret	Spouse	No	74	Female	Retired	Fair	70	120	NA	NA	NA
Susan	Spouse	Yes	68	Female	Working P/T	Very good	84	48	>15	NA	NA
Monica	Child	No	62	Female	Working P/T	Good	24	180	NA	NA	NA
Adam	Spouse	No	72	Male	Retired	Good	20	96	NA	NA	NA
Lenny	Spouse	No	71	Male	Retired	Good	168	72	NA	NA	<7
Dawit	Spouse	No	57	Male	Working P/T	Good	168	108	>15	NA	NA
Henry	Spouse	Yes	66	Male	Retired	Good	144	192	>15	<11	NA
Caroline	Child	No	57	Female	Unemployed	Fair	24	24	NA	NA	NA
Debbie	Spouse	Yes	72	Female	Retired	Good	168	184	>15	<11	NA
Gerald	Spouse	No	76	Male	Retired	Very good	168	184	NA	NA	NA
Tom	Spouse	No	71	Male	Retired	Good	165	172	>15	NA	<7
Denis	Spouse	No	79	Male	Retired	Very good	168	160	NA	NA	<7
Maureen	Spouse	No	79	Female	Retired	Good	84	60	NA	NA	NA
Gary	Spouse	Yes	80	Male	Retired	Fair	84	72	>15	<11	NA

4.1.3 Reported Carer Health and the COPE Index

From Table 10, eight carers stated that their health was fair or poor with the remainder stating good or very good. Three of the carers (Carly, Mary and Gary) with fair or poor health did score negatively in aspects of the COPE index. However, at interview three further carers who had originally stated that their health was good or very good (Susan, Tom and Maureen), did comment on the effects caring was having on their health. Susan discussed visiting her GP when *I was really desperate...because of her husband's rapidly deteriorating health*. She had experienced panic attacks (which she attributed to the stress of caring) in the month prior to the interview. Tom also commented on a recent visit to the GP ... *when I saw him I did say that you know I'm finding it more and more difficult*. Finally, Maureen (the oldest female carer who turned 80 during the study) also discussed recently being given anti-depressants by her GP after a period of insomnia and low mood.

4.1.4 The COPE Index

The COPE Index was used as a preliminary screening mechanism to identify the carers' perception of their role (Balducci et al., 2008; McKee et al., 2003) since it offers a profile of the negative impact and the positive value of the caring role, and the quality of support available. It should be noted that the following guidelines are offered in the use of the scale (Balducci, et al., 2008). There are no threshold scores for each aspect since these are continua. A particular value cannot be used to categorically determine those who are finding the role too demanding or not finding the role worthwhile or do not feel supported in their role as a carer compared to others that do. However, the guidance for the tool from the UK research showed that less than 15% of carers score 16 or more on the Negative Impact scale, less than 15% of carers score 10 or less on the Positive Value scale, and less than 15% of carers score 6 or less on the Quality of Support scale. In line with this guidance those who scored as follows; >15 on the negative impact; <11 on the positive value and <7 on the quality of support are identified in Table 10. As can be seen half of the carers in this sample had reached threshold scores on one or more items. Consideration was given to these scores when preparing for the data collection phase and in planning potential areas to explore with the carer.

Negative Impact of Caring

In terms of the negative impact of caring, four male and four female carers scored >15. The male carers appear to be disproportionately affected with 50% of them having a score of >15 (this is compared to 33% of the women). In this sub-group only one carer (Mary) was giving less than 50 hours of care per week. Three were giving over 50 hours of care per week and four were giving over 100 hours of care per week.

Positive Value of Caring

All of those identified as being below 11 for the positive value (four carers in total; Mary, Henry, Debbie and Tom) had scored > 15 for the negative impact aspect. This would indicate that they are finding the caring role stressful and gaining little satisfaction from the role. For Henry, Debbie and Tom their spouses were severely affected by the disease and were also in receipt of paid formal domiciliary care. In Debbie's case domiciliary care was started during the data collection period.

Quality of Support

From the network name/role relation data it was evident that the four carers (Mary, Lenny, Tom and Denis) who scored low on the quality of support items had restricted networks particularly in relation to those who they would talk to about their health, their role and who they could count on to support them in providing care. Although Mary was giving less hours of care than the others (35 hours per week), she was the only carer to reach the threshold scores in all three areas. However, it is interesting to note that this carer had the smallest informal network (n=6) with no close or wider family support indicated. At interview it was apparent that her worries about her Mother's health and the future alongside tensions and conflict within her network were all having a detrimental effect on her.

Mary I don't know what's going to happen with me emotionally when I do lose my Mum.

4.1.5 Occupational Status

All but five of the respondents were retired. Of the five who were not retired, three of those were the daughters (Monica, Caroline and Mary) who cared for a parent, one of which had a part time job, one was unemployed, and the other was a student. The two remaining (one male, Dawit and one female, Susan) were spouses, and both had part time employment. Triangulation with the qualitative data did illuminate more detail on the five participants who were not retired. For each there was a very personal context in relation to work and their caring role. This also tied in with other life-course changes. For some the transition away from work or to alter one's working pattern was related to the caring role but for others macro level events such as the 2008 financial crash had also precipitated change. For Mary she had decided to undertake University study after taking redundancy from previous full-time employment during the economic downturn. However, the demands of her caring role were now having an impact on her ability to complete her coursework on time. Work was viewed by the carers as offering a further social dimension away from caring and for Caroline greater financial independence. Susan was at the stage where she could be semi-retired from her original role but had just signed a contract to return for two mornings per week. It was evident that this time outside the home, away from her caring role was beneficial as the following excerpt shows.

Susan: If it was a dreadful job then no, I wouldn't be going...but its lovely to get up and go out...and know that Derek is being cared for...

JS: Because [the paid carer] might be here...?

Susan: And...yeah it's just the camaraderie of being with other women....

For Caroline there was an ambivalence about losing her job and becoming unemployed. It had coincided with her needing a routine operation and having to care for her father. She had therefore needed the extra time and flexibility to support him. However, the loss of income and independence from her husband were also commented on in the following discussion that took place at the interview.

JS: do you miss..... work? Had your Dad been diagnosed when your job went or was that about the same time...?

Caroline: It's about the same time so in a way it was a God send.....

JS: *And things changed?*

Caroline: *Yeah because in that year with Dad as well going backwards and forwards to the hospital...and it was all different times, I mean one, one day we had to go up twice, once in the morning and once in...like late afternoon, so that was the day gone coz you can't do nothing in-between...*

JS: *.....would you miss the work or the social interaction...?*

Caroline: *I do miss work...I do, I miss work, I miss the money.....My own independence, I could do what I wanted although.....I had my little bit, I could go and buy what I wanted to buy...whereas now I have to rely on my husband and I don't like that, I don't like...to have to ask, I mean he don't begrudge it but he don't earn that much, you know ...but...its...hard.*

Flexibility in her working life, had enabled Monica (a Doctor) to continue working very part time while she had been a carer for her husband (who had subsequently died) and now for her father. Monica had found being able to return to work helped after her husband's death but her working life was secondary to her caring role.

Monica: *...the best piece of advice I had after my husband died was just keep incredibly busy and you know as...and just then you have less time to think about it, just keeping going and then some of its therapeutic.*

And later:

Monica: *I have no regrets about that [giving up much of her work], I would far rather have err...been caring and that's the same I feel about my Father you know, if I have to give all the other up that's fine...*

4.1.6 Demography and Family Structures

The 20 participants were a heterogenous group. Four of the carers (Carly, Lenny, Julia, and Dawit) were migrants and each of these had family overseas. For Carly, her two sons were in the southern hemisphere and Lenny, Julia and Dawit all had siblings abroad. Eighteen of the carers were married and as previously stated 17 of these were

co-habiting spouses. Two of the couples were also childless (Cilla and Julia). Caroline was a married daughter with her own children caring for her father and finding herself in the sandwich generation (Brody, 1981; Miller, 1981). As for the remaining two carers (Mary and Monica), these were both daughters one caring for her mother the other her father. The former was single and an only child whereas the latter was widowed. Both did not have children. Three of the co-habiting spouses were in a second marriage (Carly, Elizabeth and Lenny). For Elizabeth and Lenny, their partners had children to a previous marriage and for both carers these stepchildren were involved to a greater or lesser extent in supporting the carer.

4.1.7 Living Arrangements

Although spousal cohabitation predominated there was a range of living arrangements for those caring for a parent and these exhibited a degree of flexibility dependent on the needs of the care-recipient. Monica during the period of the study, moved in with her father due to his increasing frailty. For Mary and Caroline living arrangements were flexible with Mary spending nights at her mother's home and Caroline seeing her father daily and having him to stay regularly at her home. Five of the participants had children living with them (Dawit, Henry, Caroline, Debbie and Tom). In the case of Caroline, one of her sons was under 18 years old. Dawit had an adult son at University who returned home in the holidays. Both Debbie and Tom had an adult daughter and grand children living with them. For Debbie this was her youngest daughter who lived in the house with her husband and son. From the interview it was evident that her daughter and son-in law could not afford to move out. In the case of Tom, his daughter had returned home with her son after getting divorced. His daughter had been living with them for nearly 10 years since the divorce. In Henry's case, his adult unmarried son lived with him and his wife.

4.1.8 Other Caring Responsibilities

As described by Fast et al., (2020) there were a range of caring trajectories across the carers life course that reflected their own biography. Most of the spousal carers followed a compressed care trajectory (with care in later life to their husband or wife) or a broad generational trajectory (where their caring role had begun in mid-life, when

their partner's PD had been diagnosed). For two of the adult daughters their care trajectory was that of intensive parent care, however one daughter had previously cared for her mother and her husband consecutively followed by her father and thus had followed a serial care trajectory. Finally, three carers had cared for a child with severe physical or learning disabilities thus theirs would be classed as a career care trajectory.

4.2 Summary

This chapter has introduced the participants and presented some key demographic data. The COPE Index (Balducci et al., 2008; McKee et al., 2003) was a useful tool to gain insight into the carers' perception of their role and acted as a preliminary guide in planning and considering how to approach the questions and areas to explore during data collection. Across the 20 participants that was heterogeneity in terms of their living arrangements, family structures, health, and occupational status. In Chapter 5, this heterogeneity will be further explored in The Carer's Personal Community with reference to their informal networks of support.

Chapter 5: Results

The Carer's 'Personal Community': Bonding Together and Bridging Beyond

5.1 Introduction

This chapter is the first of three chapters that address the findings of the study. The findings from the data analysis will be examined with reference to those informal networks (friends, family, and neighbours) that offered support to them in their caring role. It will particularly address the following questions posed in the study:

- What are the forms, functions, and associations of carers' social networks?
- How do carers access and utilise the resources contained within these networks?
- How do their social networks impact on their caring role?

In relation to the final question:

- What is the role of the health and social care sectors and the local community in shaping or developing carers' social networks?

The place of the local community alongside health and social care within the carers' networks will be briefly described. However, a more extensive analysis of these aspects will be given in Chapters 6 and 7. Social network analysis utilising both structural and 'convoy' perspective (Antonucci, 1985; Antonucci et al., 2009; Cantor, 1979; Cantor, 1991; Kahn & Antonucci, 1980) allowed consideration of the differing components that formed the carers' social network. Structurally, composition, size, contact frequency, and proximity were all elucidated with an emphasis on the convoy of supportive individuals who surround the carer from the informal network of family, friends, and the immediate community. From this it was possible to uncover the carer's 'Personal Community.' This term will be utilised since it appeared more fitting since it captures the uniqueness of each carer's network.

A 'personal community' is defined by Pahl and Spencer (2010) as follows:

By personal community, we refer to the set of personal relationships that a person considers important for him or her at a particular time (Pahl and Spencer, 2010, p.205).

To examine the carers' personal communities this chapter is organised into two sections as follows:

- Section One: The Carer's Personal Community: Demographics and Personal Biographies Shaping the Network
- Section Two: The Carer's Personal Community: The Network in Action. Accessing and Utilising Resources

Each section will examine several themes, subthemes and intersecting elements arising from the data analysis (see Table 11). The results will reflect the data obtained from the network generator questions and is further illustrated by sociograms of individual carer's network data. Diary and interview excerpts will further elaborate on the form, function and complex social interactions that formed the carer's network of relationships.

5.2 Section One:

The Carer's Personal Community: Demographics and Personal Biographies Shaping the Network

Within each carer's personal community were family, friends, and neighbours but for each carer this varied with some networks dominated by family whereas other were dominated by friends. The analysis of the various forms of data (social network structures through the name generator questions, interview and diary data) with triangulation enabled a detailed picture for each participant to be constructed. From the qualitative analysis it was evident that these had been shaped over time and were dependent on the carer's unique personal biography and family history, demographics and geography. However, it was also evident that the care recipients' illness, the caring role, and the carer's involvement with groups such as Parkinson's UK

Table 11: The Carer’s Personal Community: Concepts, Themes and Subthemes

Over-Arching Concept	Theme	Sub-theme	Key Elements
The Personal Community: Bonding and Bridging	Demographics and Personal Biographies Shaping the Network	The Network Typologies incorporating: Family Structures Friends and Neighbours Community and Third Sector Organisations Health and Social Care	Gender Geography and Migration Intra and inter-generational support <ul style="list-style-type: none"> • Children • Siblings • Wider Family Old and new friends TSOs and Community Groups Faith and the Church
	The Network in Action	Facilitators and Barriers to Support The Carer as a Network Bridge, Broker, and Co-ordinator	Reciprocity and Mutuality Ambivalence, Conflict and Tension Navigation and Negotiation

and other community-based organisations) had influenced the structure of their network and led to potential and actual support and resources. The network generator questions identified different alters in the carers' network, the basis and closeness of the relationship, their proximity and frequency of contact. From this it was possible to create a classification of network types for the carers in this study. These will be presented alongside key themes that intersected and shaped the carers' networks.

5.2.1 The Network Typologies

In examining each carer's personal community, it was possible to classify the carers' networks. Questions one to six of the network generator questions were used to give the classification of each typology based on the relational properties of key informal alters in the network (i.e., family and friends), the support that they provided alongside their proximity and how regularly face to face contact was made. This allowed the 'everyday' bonded social network to be uncovered. However, questions seven to ten allowed a more detail examination of those viewed as supportive with care and more specifically who could be relied on to support in providing care. These questions also gave details on the role of the wider community and more formal health and social care provision currently involved with the carer and care-recipient. It should be noted that by virtue of how the carer was recruited each care dyad was involved with at least one community group i.e., Parkinson's UK at some level. For the main category of 'family and friends' on analysing the interview and diary data distinct themes became apparent between the networks that were classed as 'local' and 'dispersed' (see Table 12). In the local typology, the carer's family were within half an hour's travelling distance.

The other two major categories captured the two remaining carers who participated in the study. One carer (Mary) did not name any family (separate to the care-recipient) in questions one to six and was therefore categorised as local friends only. The other carer (Caroline) did not name any friends in questions one to six and was therefore categorised as local family only. Table 12 outlines each category with the key themes that were apparent either within or across the categories. Each typology will be presented, and the themes that were uncovered will help to explain the network

Table 12: The Network Typologies

Network Typologies	Features	Key Elements	Carers
Local Family and Friends	Face to face contact occurs with family and friends on at least a weekly basis. Within each alter group one or more are within ≤ 30 minutes travelling distance to the carer.	Reciprocity and mutuality Intergenerational support Siblings Church/Faith	Elizabeth, Margaret, Adam, Dawit, Gerald, Maureen, Denis, Debbie
Local Family and Friends with Direct Formal Care Provision	As above with at least weekly direct formal care received either in or outside the home.	Parkinson's UK and Community groups Culture Transitions	Susan, Henry, Tom, Gary
Dispersed Family with Local Friends	Face to face contact with family is $>$ weekly. Face to face contact with friends is at least weekly. Family are >30 minutes distance from the carer. Friends are <30 minutes distance from the carer.	Migration Suffusion Childlessness	Carly, Julia., Monica Lenny, Harriet
Dispersed Family with Local Friends with direct formal care provision	As above with at least weekly direct formal care received either in or outside the home.	Parkinson's UK and Community groups Old and new friends Transitions	Cilla
Local Family Only	No friends are listed. Face to face daily contact occurs with the family. The wider family is within ≤ 30 minutes travelling distance to the carer	Sandwich generation Suffusion	Caroline
Local Friends Only	Except for the care-recipient, no family are listed. Face to face contact occurs with friends on a weekly basis. Friends are within ≤ 30 minutes travelling distance to the carer	Single, only child Parkinson's UK	Mary

structures and their function. To aid this discussion, several detailed egocentric maps will also be presented (see chapter 3, section 3.11.7 for more detail on how these were constructed). These maps allowed for comparisons across the participants and the discussion will highlight where differences are evident alongside the significance of these differences in a particular network typology.

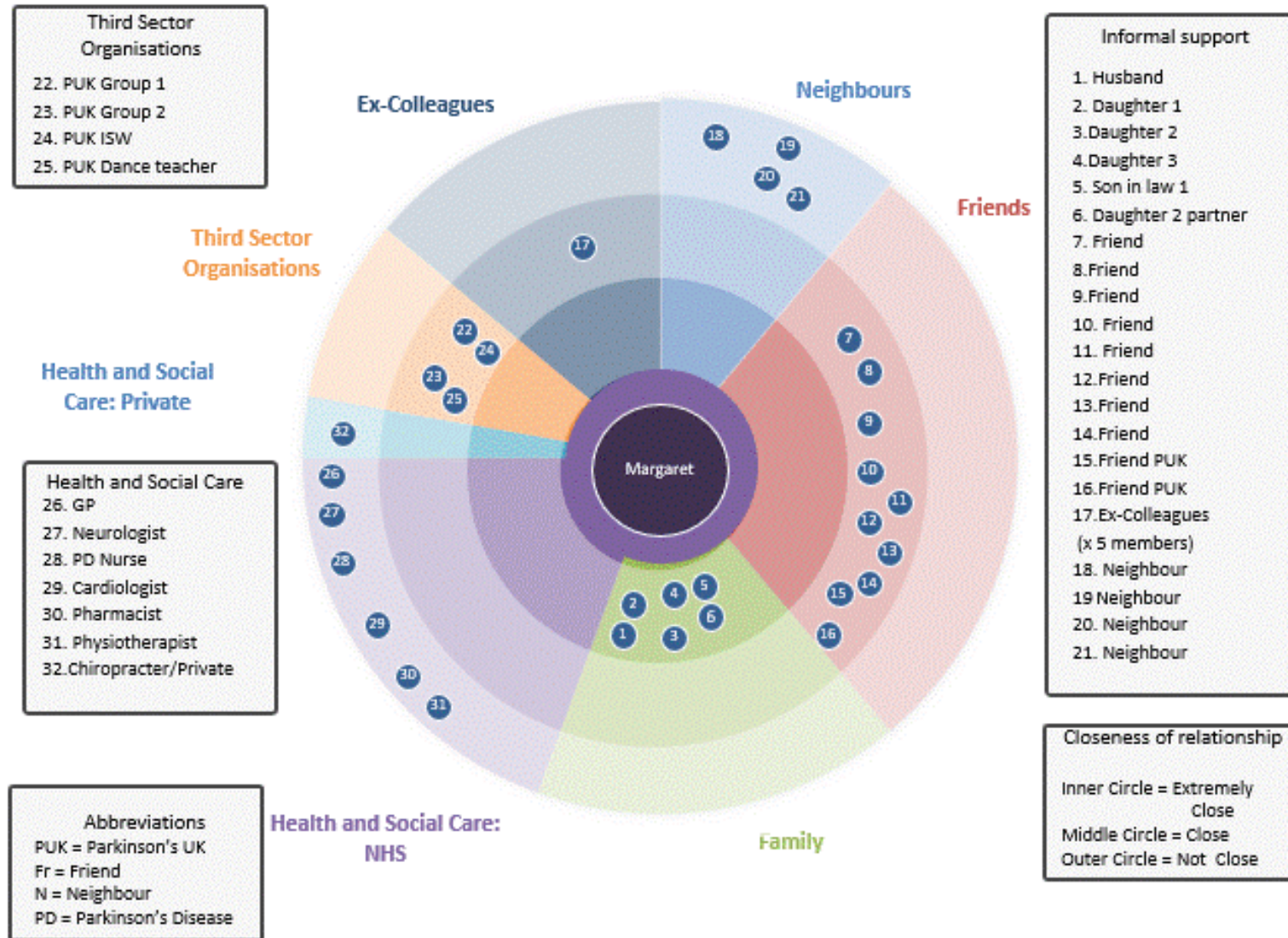
5.2.2 Local Family and Friends including those with Formal Care Provision

In this category all the carers (n= 12) were cohabitating spouses and had children or in the case of Elizabeth, stepchildren. Overall, the carers had a range of friends and relatives who lived locally and who they interacted with at least on a weekly basis. Neighbours featured in most of these networks and were listed particularly for instrumental support such as borrowing equipment. The informal networks in these subcategories were the largest (range n= 10 to 24). Family activities and regular (sometimes daily) contact were evident in the carers' accounts and the diary data. During data collection, four within this group diarised or discussed family celebrations that had recently taken place for birthdays (including a carer's 80th birthday) and a special wedding anniversary.

Figure 3 is the egocentric network data for Margaret. This carer's network is typical of this typology. Margaret had been married to Jim for over 50 years and had continued to live in the same area throughout her married life (as was the case for nine of the other carers in the local family and friends category). As the network diagram indicates Margaret had three daughters and all were included in her informal network of support. One daughter who was local offered regular instrumental and emotional support to Margaret and Jim. Many of their friends they had known throughout their married life and some of these now offered emotional and instrumental support either directly to the care-recipient or to Margaret as the carer. The neighbours were also discussed in terms of actual and potential support, and this included taking Jim out to give Margaret some respite time. It was apparent that as a couple they had enjoyed a varied social life and the diagnosis of PD had for them opened-up other social opportunities through their membership of Parkinson's UK.

A third of those with local friends and family were receiving regular social care provision. This certainly supplemented any support received from family and friends,

Figure 3: Local Family and Friends-Margaret

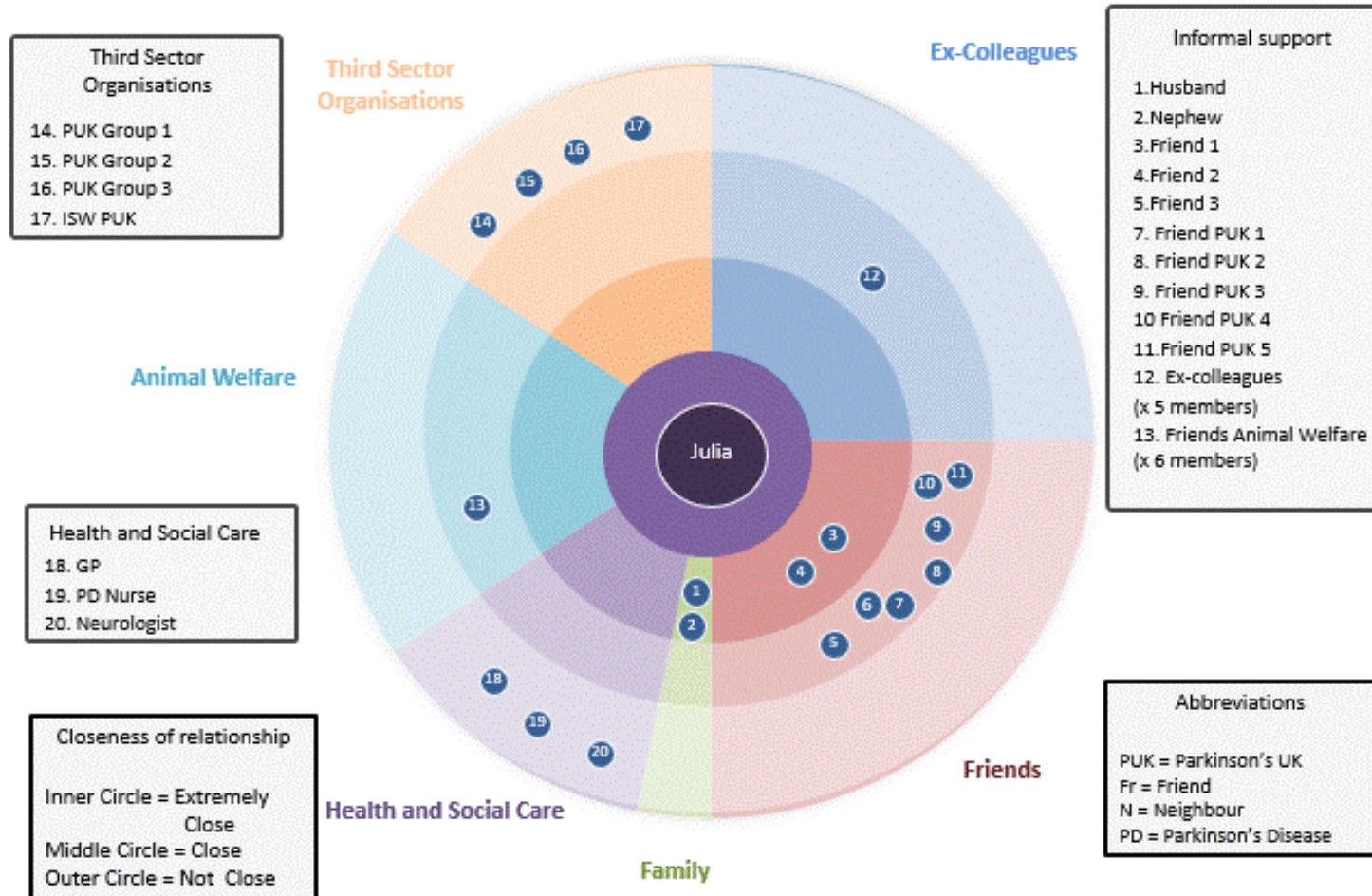


but it was difficult to ascertain if the introduction of informal care had led to an alteration in any informal support that was previously given. The care-recipients in these cases were severely affected by the disease. It should also be noted that during the study, Debbie's spouse also began to receive domiciliary home care after a period of hospitalisation. In Chapter 7 the role of formal care provision in the network will be closely examined.

5.2.3 Dispersed Family with Local Friends including those with Formal Care Provision

Within these categories the carers (n=6) were a far more heterogenous group. Geographical distance due to international migration and the movement of family members due to work commitments alongside individual biographies and life course events such as childlessness, contributed and shaped their egocentric network data. Within this category, Cilla's husband was the only care-recipient who had regular formal care outside the home at a local, charity organised luncheon club. The networks in these sub-categories were smaller (n= 7 to 22) with fewer family members listed. A feature of this typology was the significance of friends within the network particularly in terms of their support to the carer in their caring role. Figure 4 illustrates Julia's egocentric network. Julia had migrated to the UK many years previously and met her UK born husband. The couple were childless, and the main family contact was their nephew. However, the network contained several friends these had been developed through their working lives and the couple's involvement with Parkinson's UK and over many years, other community-based groups. One of these friends was named as being particularly close and supportive to the carer and care-recipient.

Figure 4: Dispersed Family with Local Friends-Julia



5.2.4 Family Only Network

Only one carer (Caroline) was in this category. In the name generator questions no friends were included. As a middle-aged carer Caroline would be classed as one of the 'sandwich generation' given she was looking after her ageing father whilst still caring for one son under 18 years and with three other adult sons who all lived at home. Her informal network was small (n=7) although the interview data indicated that the network was beginning to change as the carer had become more involved with a Parkinson's UK group and friendships appeared to be forming with individuals associated with that group. Interestingly although Caroline was married her husband was not named in any of the name generator questions. Her principal support was gained from her oldest son and a female cousin. Both were central for her social and emotional well-being. Figure 5 illustrates this typology.

5.2.5 Friend Only Network

Mary was the only carer in this category. Mary's biography meant that involvement of a wider family network was not possible, and the informal network was one of the smallest (n=6) of all those in the study. As an only child, who was single and without children, she cared for her mother. Mary's Mother was divorced, and Mary was estranged from her father. Also, there was a personal rift with her mother's family who were predominantly overseas in the EU and therefore no support was provided by them. Figure 6 illustrates this typology.

It was interesting to note that Mary's score on the COPE Index was negative in all three areas. During the interview Mary acknowledged that she found it difficult to ask for help and related that to her independence and only-child status.

Figure 5: Family Only-Caroline

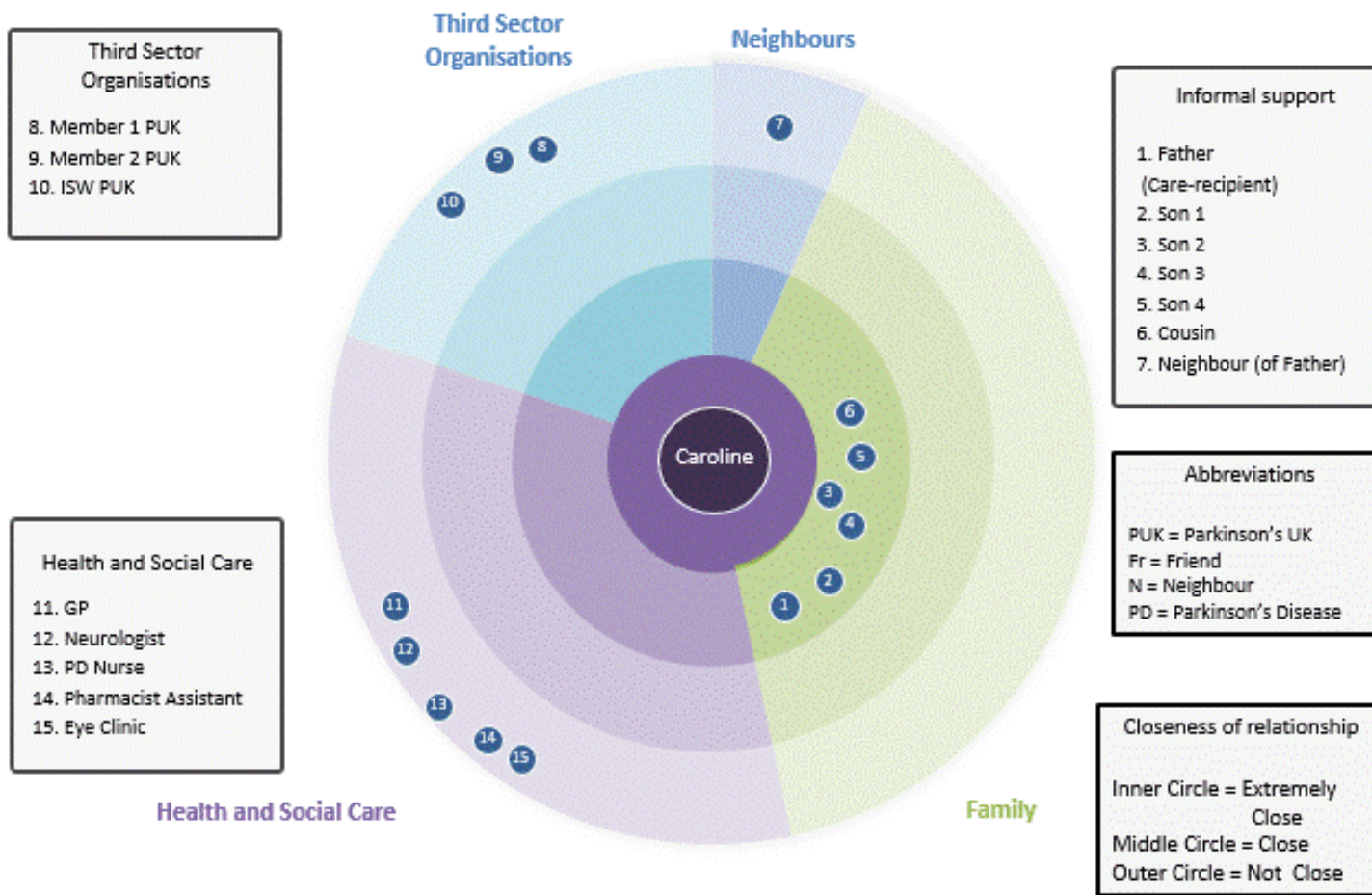
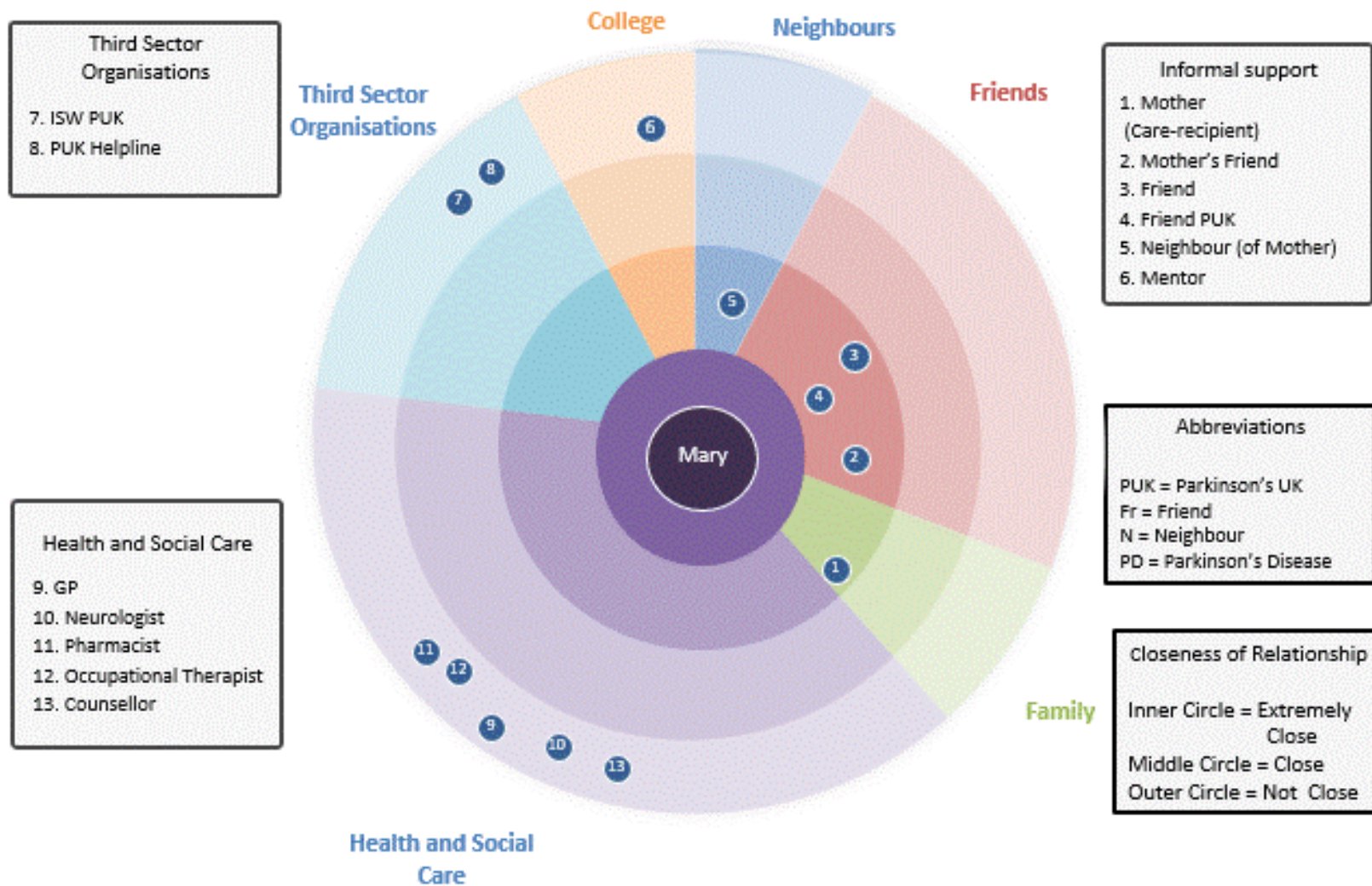


Figure 6: Friends Only-Mary



5.3 Intersecting Elements that Shape and Determine Carer Support

On examining the structural forms, functions, and associations of the networks several intersecting elements were apparent that certainly shaped the carer's network and therefore determined who they may turn to for help and support. Some elements were more evident in certain typologies compared to others. Thus, in presenting these elements, their relationship to the different typologies will also be explored.

5.3.1 The Network Typology and Carer Support

Following on from the identification of those who were part of the carers' informal networks, the responses to question seven to ten identified individuals within that network who gave support in relation to the following:

- Who they talk to about their own health, or count on when they have a physical or emotional problem?
- Who they talk to about the health of the person they care for?
- Who they talk to about their caring role?
- Who would they count on to support them in providing care?

The support that the carers received in relation to these varied by the typology. The data for the two larger typologies has been tabulated (see Table 13 and 14) and presented to highlight key differences. From Table 13 (the local family and friends typology), the role of daughters stood out as a significant source of support. In the dispersed family group (Table 14), other family and friends were identified for support by proportionally more of the carers in this typology compared to those with local friends and family. There may be several explanations for this according to each carers' circumstances. Only two carers in this typology had children (sons) who were living some distance away. Thus, in the absence of filial ties, geographical distance, and the dominance of friendships in the network meant that other wider family or close friends (some who were kin-like in nature) were identified.

Table 13: Support Given to the Carer by Alters within the Informal Network: Local Family and Friends

Typology	% Of carers turning to key alters re:	Spouse (n=12)	At least one daughter*	At least one son*	At least one other family member	At least one friend
Local Friends and Family n=12	Talking about own health	25	85	25	42	50
	Talking about care-recipients' health	17	57	25	42	17
	Talk about caring role	0	57	25	42	58
	Who would support for caring	0	100	25	42	17
		All care recipients in this typology are spouses	Seven carers in this typology had daughters	Eight carers in this typology had sons		

Table 14: Support Given to the Carer by Alters within the Informal Network: Dispersed Family and Local Friends

Typology	% of carers turning to key alters re:	Spouse (n =5)	Parent care Recipient (n=1)	At least one daughter*	At least one son*	At least one other family member	At least one friend
Dispersed Family and Local Friends n=6	Talking about own health	33	0	0	0	50	50
	Talking about care-recipients' health	33	0	0	0	50	33
	Talk about caring role	17	0	0	0	50	67
	Who would support for caring	0	0	0	0	50	67
		Five care recipients in this typology are spouses	One care recipient in this typology is a parent	No carers in this typology had daughters	Two carers in this typology had sons		

The family only and friend only networks are not tabulated. Caroline, who identified only family in her informal network, did not name her husband but named her eldest son and a female cousin as key alters for support. At the interview she did, however, identify an individual who she had recently befriended in the Parkinson's group and with whom she discussed her caring role. For Mary, two of the three friends she had listed in her informal network, were identified for support with her caring role

5.3.2 Gender

Of the 20 carers that were recruited 12 were female (nine spouses and three daughters) and eight were male (all spouses). Most of the care recipients, 11, were male. Thus, in this group proportionally there were more female carers. The addition of daughters (not sons) caring for their parent meant that the number of female primary carers in this study is 1.5 times that of male carers. Table 13, and other aspects of the data, particularly highlighted gender and the role of daughters in assisting the carer or providing direct care to the care-recipient. Thus, where carers had a daughter(s), these were the dominant alters accessed for support by the carer. Table 13 demonstrates that all respondents with a daughter expected that their daughters would support them in providing care. Thus, both mothers and fathers identified their daughters in this respect. However, only 25% expected that their sons would do the same. Of the three adult-child carers who participated in this study all were daughters. Furthermore, when examining the informal network across the cases, women predominated as those who the carer might turn to for support in terms of their caring role. The cumulative proportion of women: men named across all the participants' informal networks (as obtained from the responses to questions one to six) was 54%: 46% and yet in terms of support for the carer (questions seven to ten) this proportion changed to an increase of 63% for women and a decrease to 37% for men. Therefore, alongside daughters, sisters, sister in laws, female friends and stepdaughters were all identified by the carers as being sources of support for their caring role.

5.3.3 Network Size

Both the friends only and family only networks were small (n=6 and n=7, respectively). This therefore severely limited the availability of alters who might provide support. For Mary, three female friends were identified in the informal network. Two were then named in terms of supporting Mary in her caring role. One in relation to talking about

Mary's health and about her caring role, whereas a friend from the Parkinson's UK group was identified for support with care

5.3.4 Geography and Migration

An important factor that affected the network features and interactions was the level of geographical mobility that is a feature of modern society. As described in section 5.2.3, individual mobility was a determining feature of the Dispersed Family and Local Friends network. In this typology were three of the four migrants who participated in the study (Carly, Lenny and Julia). Thus, although family members were named there were limited opportunities for regular contact and instrumental support from those family members. For Carly, her children, family and many friends were overseas, and this was the same for her husband. They therefore regularly used Skype™ and email to maintain contact. For Lenny, all his siblings who had migrated with him to the UK had now returned to their homeland. He was close to his brothers and sister overseas and maintained regular telephone contact with them which provided emotional support. Thus, Lenny's only family in the UK were his wife and his two stepchildren and his informal network was one of the smallest in the study (n =6). Similarly, Julia had no family in the UK and the only family named was a nephew on her husband's side. Others (Susan and Harriet), whose children were in the UK but some distance away, only had intermittent face to face contact across the year and no regular instrumental support was possible. These carers also used Skype™ and Facetime™ to maintain contact. Both Harriet and Carly's children had wanted them to move (or in Carly's case leave the UK) to be closer to them. Neither wanted to go and both had very established networks where they lived.

Harriet: I mean he [the son] has said...who don't you move near us?...No way would we move near you...we've got our life here you know...and also we know people who have moved to be near their children and their children move on...the children change jobs, they...they don't always stay in one place...they're young you know their life is...you can't follow your children around...

Across the participants others maintained social contact with and received affective support from siblings, sibling's in-law and friends by varying means of electronic

communication. Debbie emailed her sister (who lived almost 1.5 hours away) most days and with phone calls and texts, she found this uplifting. In this extract Debbie laughed as she talked about comparing notes in their email that day.

Debbie:....so of course she wrote today saying she's got these 4 [medical appointments coming up] , so I said haha, I said we've only got one medical appointment, but we have got a carer who couldn't put the pad in the right place, couldn't clean his teeth couldn't do anything else, so I said, So there! (laughs)...

Therefore, propinquity certainly had a significant effect on the structure of the network and availability of support for the carer and care-recipient although for some different modes of electronic communication were evident which acted to supplement affective support and maintain social contact.

5.3.5 Bonding Ties: Intra and Intergenerational Support

The role of kin in supporting the carers in their role was evident and was a feature for many of the participants. Most respondents identified immediate family as significant members of their social network and many were the most likely to provide support in terms of assistance to the carer in their role and through direct care to the care-recipient. For those without children, wider-family support was discussed and particularly nieces and nephews. The overall support provided varied based on individual circumstances and biographies. All except Mary, had family members that they would turn to for support. This would support both the functional specificity and task specificity models (Simons, 1984; Sutor et al., 1995; Perry and Pescosolido, 2010) of care access.

5.3.6 Children: *But they're all so different...*

The role of children in supporting the carer through direct help to the care-recipient or assistance to the carer varied greatly and was dependent on age, proximity and the relationship with the carer. A range of social, emotional and instrumental support was provided, although the carer often singled out one child that was most supportive.

Margaret had three daughters that were involved in supporting her and the care-recipient but in quite different ways. Her eldest daughter was tasked with advising on

their finances and had Lasting Power of Attorney whereas her middle daughter had a complicated life after a divorce and was a single mother. For this child, Margaret often helped with the Grandson's care and had supported her daughter financially. However, it was the youngest daughter, who lived close by, who was singled out for the support she provided. This was based on her attributes and circumstances when compared to the other two.

JS: ...so what is it...is it just the fact Kathy gives you a lot of what, emotional support or practical support...?

Margaret: Yeah, she does ...umm like last night we came in from London at half past five and then we had to be over at the chiropractors in [place] at half past seven..... ..and she came in with a cooked chicken...coz I said to Jim what are we going to do...because it's too late to cook ...and she said right Mum...I've got a cooked chicken...she said umm...I'll peel the potatoes or scrape the potatoes...you do the peas and the broad beans...and between us we did it...she's brilliant...she's a lovely girl...I love her...

Henry also had three children and their involvement with supporting the care of their Mother and Henry varied partly on geographical distance, propensity and gender. Henry initially discussed the involvement of his son and daughter who both lived over an hour's distance from his home.

Henry: [The son] he's not...as reliable I would say as sort of Emily umm...but again it's a boy girl thing you know really, umm you know whereas Emily will phone me up and say how's it going, With Teddy it has to be the other way around, you have to phone him and say you know, umm it's about time we saw you sort of thing (laughs).....

Greg, Henry's youngest son lived at home and was also willing to support his father.

Henry: ...he also is very helpful as far as Sandra is concerned, he regularly err will look after Sandra on a Sunday evening, when I go to the pictures or

whatever, and he will quite often err...if he is around and so forth, help me to sort of pop out for half an hour for a walk or whatever...

However, Henry was also conscious of not asking too much of his children.

Henry: You know, they're, I feel they have their own lives to lead and so forth and that I don't want to sort of...impose upon them more than...I have to really you know.

For several carers there was a hesitancy about expecting help and support since the carers didn't want to limit or burden their child(ren). For Dawit his son was younger and starting out on his own adult life.

Dawit: I try not to burden him...although..., my wife seems to like it when he helps her...umm...I think we had this erm...discussion with [friend] and her husband... ..they've got two children and he's of the view that err...oh they must know, they must help and I'm I was quite the opposite saying that you know...give them time you know, they're young still, teenagers and ...let's not burden them.

Several of the carers emphasised the demands on their children in terms of work and home life and were conscious of the impact this had on the support that could be given.

5.3.7 Stepfamilies

The changing nature of family relationships and structures was also evident with two of the carers married to partners who had previously been married and had children from that relationship. As such, Lenny and Elizabeth had stepchildren and neither had their own biological children. The relationships across these two carers with their stepdaughters and a stepson in Elizabeth's case were quite different.

Lenny's stepfamily consisted of two older daughters and although they did not live locally, they were very proactive in directly supporting their Mother, Eve, whilst also supporting Lenny. Lenny's network was one of the smallest in the study (n=7) and he

appeared a quiet, solitary man. In discussing help and support he made the following comments about his wife and her daughters.

Lenny: *I haven't got many friends...you can say that...they are my friends...yeah...*

For Lenny there was a blurring or suffusion (Pahl and Spencer, 2004) of the roles of family as friends. In his relationships with the stepdaughters there was a sense that they helped to direct and guide Lenny in his caring role. It had been Sally, one of the stepdaughters who had first alerted Lenny to her mother's shaking hands and this had initiated the family to seek medical advice that led to the PD diagnosis.

Lenny: *...there was shakiness in one of her hands...and like umm...Sally observed that...because we go over to them from time to time.....And err...she said... like she'd say to me or ask me...Lenny have you noticed that Mummy has a shakiness in, in one of her hands...umm...I said...ahh...to be honest I would say...I, I hadn't noticed it that, very much, but she said, I, I've noticed it she said and umm...and how is she coping and so on and so forth...yeah...*

Later in the interview:

JS: *... and the girls...so..... you've obviously got...it sounds like you've got a good relationship with the girls...*

Lenny: Yes...and that's been, and that's been fine really coz they do help you with the care..... Because if Sally especially if she's, in, in, in doubt about something regarding her mother...she would say...be honest now and tell me the truth...

For Elizabeth the relationships with her three stepchildren (two daughters and a son) varied. As their father's second wife, there had been tensions early in the marriage and it had taken some time for Mark's daughters to meet with Elizabeth. However, over her thirty years of marriage to Mark she had grown close to one of the stepdaughters, this relationship had changed more recently and this, Elizabeth believed, was linked to the

sale of the family home, the financial expenditure on care and gifts of money that had been given to members of the family. Elizabeth felt that although this daughter (and her children) had benefitted from these gifts, it may not have been the amount expected and there was possibly a concern about the future inheritance.

Elizabeth: I know money is at the bottom of...the deterioration of my relationship with Lydia...I don't know what it is with Lydia now.

5.3.8 Siblings

Striking in many of the carers' accounts was the role of their siblings alongside sister and brother in-laws in providing support and care to the dyad. Siblings would constitute the carers' most long-standing relationships and it was apparent that for some this had become more significant to the carer as the care trajectory progressed. For most the support was principally emotional although in some cases particularly where the intensity of care for the care-recipient was increasing siblings had also become important instrumentally.

Susan: She's my sister...she's a good friend... We're very close

Susan spoke with great affection about her younger sister (Winnie). During the interview she continued to text and spoke to her sister on the phone since she was travelling to their ailing stepfather, and Susan wanted to know that she had arrived safely. They had not always been close but over the years both had supported each other during family crises particularly in relation to serious illness. They now met socially on a weekly basis and rang each other regularly too. Again, as described by Pahl and Spencer (2010) there was a blurring or suffusion of Winnie's role as their relationship had become much closer and more friend-like. Early in the interview Susan made the following comments.

JS: ...who's got the most positive effect in terms of caring...?

Susan: Winnie...without a doubt...

JS: Your sister....what is it then about Winnie's support...?

Susan: She's...she's well...she's my sister...she's a good friend... we're very close.... She's just very supportive and...we just get on very well...

JS: *And is it mainly sort of emotional support really then...?*

Susan: *Its emotional support...its...its...friendship...its...oh
ahh...its...understanding...its listening...caring...*

Elizabeth also spoke at length about the instrumental and emotional support that her brother was providing. It was a unique situation since Charles (her brother) was acting as a paid carer to Elizabeth's husband Mark. Charles was close to retirement and had been considering his options in relation to continuing with work. At the same time Elizabeth had been finding it increasingly difficult to manage her husband's physical care and felt unable to leave him for long periods. She likened her situation to being *under house arrest* and described her *loneliness and isolation* having always been a *sociable person*. She had become increasingly *frightened* that Mark may be taken seriously ill while she was on her own since she'd had a number of emergency visits to the local hospital. Elizabeth had the financial means to consider overnight care for her husband. On discussing this arrangement with her brother, it was decided that Charles would leave his job and they would pay for him to take care of Mark from early morning, so that he could shower him, allowing Elizabeth to leave the house and have some respite. The arrangement had been in place for several months and it was obviously working well for both Elizabeth and her husband.

Elizabeth: *Mark and Charles had a really good relationship also and Charles is a very affectionate person...I know sometimes you see that Mark's a sort of father figure to him...you can see this...he almost physically restrains himself from giving him a hug...its really nice...and Mark feels very comfortable with him...he's not...he doesn't say a lot, you just know...I mean you know this is affection...so somewhere in my youth and childhood I must have done something good (laughs)...*

Within the diary there were daily accounts of Charles' visits with extra phone calls from her brother offering emotional support and regular contact throughout the day.

Dawit described the assistance he received from his brother (Aman) who lived locally and sister who lived abroad. The diary data illustrated their contact and captured their particular care for him and his wife (Zara). Dawit and his wife regularly saw Aman in a

social context meeting at his home where he cooked them dinner, giving Dawit some time to relax. Given that Dawit's sister was abroad, social contact was restricted but they maintained weekly contact via the telephone. As was evident from a diary entry provided by Dawit, his sister's emotional support was important.

My sister phoned to see how we are coping. She is probably the only one I share my feelings and emotions. She is a good listener – active listener and genuinely interested to listen to what I say and offer me support.

Dawit [Diary Entry]

Through their concern for their sibling, regular contact and support was often provided for the carers and care-recipients by sister in-laws and brother in-laws. Several of the carers discussed the role of these in-laws during the interview and they also featured in their diary entries. Henry, Gerald and Gary all commented on how their sister/brother in laws maintained regular contact and, where possible, would visit every few weeks (despite living some distance away) to see their sisters who were affected by PD. However, increasing age, their own life transitions with family bereavement and personal illness were beginning to impact on the regularity of their visits.

5.3.9 He's Away, Away from it All

At the time of the study this sibling support was contrasted by the minimal involvement of the brothers of two of the adult daughters (Caroline and Monica) both caring for their fathers. For these two daughters the peripheral role that their brothers had played in the care of their ailing parent was discussed. Both carers offered rationales for their brothers limited input based on them working, having other family commitments, and being geographically distanced from their parent. The close relationship between the carer and their parent also appeared to affect or limit the other sibling's involvement

Caroline: *He's away, away from it all, I mean...he does do things but...sometimes it would be nice like if he...I mean at, at Easter he rung up, out of the blue and said to Dad, oh would you like to come up on the Friday, on the Friday, and I'll pick you up on the Friday and...bring you home like Monday...and...Dad said oh I don't know, you know, I'll have to ask Caroline,*

this is what he said, and I said, you don't have to ask me nothing, you're an adult...do what you want you know...(laughs).

For both daughters, the limited contact by their brothers meant that there was little insight into the care-recipient's health and day to day situation.

Caroline: Well...I, I've said things, different things to him [her brother], but I don't think he understands really what's involved...he's not been around him...enough to...realise like because I think me Dad's good at putting an act on in front of him to look like he's not as bad as what he is, you know.

Overall, many of the accounts demonstrated the nature of the support provided by siblings and siblings in law. Although the support varied according to individual circumstances and geographical distance, it was evident that for some, the longevity of the relationship, their shared biographies and mutuality of support illustrated the strength of these sibling bonds. The maintenance of these relationships via regular face to face contact or other electronic means was important and offered both emotional and for some instrumental support. However, as described in the literature the adult-child carers in this study found that their siblings although available for some 'back-up' care (Leinonen, 2011, p.308) they did not appear to fully understand the position of their parent or recognise the needs of the carer.

5.3.10 Wider Family

In four cases individuals were identified from the wider-family who would support the carer and/or the care-recipient. Nieces and a nephew were identified in those carers who were childless (Cilla, Monica and Julia). Each of these carers had a dispersed family with local friends but they each had a close relationship with their niece or nephew. For Cilla and Julia, they were identified as next of kin. In Caroline's case (her network was small and family-based), a female cousin was identified as a primary source of social, emotional, and instrumental support. This cousin was experienced in care work and had offered to look after Caroline's father if his condition required it. In this case too, there was a blurring or suffusion (Pahl and Spencer, 2010) of roles since she was identified as Caroline's best friend. Monica had a network of wider family (in-laws, cousins, and a niece that she could turn to). Monica, and several others in the

family, were medically trained and her father's health was often discussed with these family members, thus enabling her to access detailed medical advice from them and their contacts.

5.4 Friendships: Old, New and Changing

For many of the carers, friends played an important role in their lives. The numbers of friends listed in the name-generator questions varied from 0 to 19. Thus, the involvement of friends varied according to individual circumstances and the personality of the carer. The involvement of friends was a feature for those carers with dispersed family, or those who had few family members or no close family available for support. In these cases, the importance of friends within the personal community was significant. Many of the carers actively sought opportunities to utilise their friendships as an escape from their caring role, or develop new friendships with those in similar circumstances, with an understanding of PD and the role of the carer.

Some of the friends listed spanned a lifetime and were close to both the carer and care-recipient. Other friendships had developed more recently and had been as a direct result of the illness as the carer and care-recipient had become more involved in Parkinson's UK or other carer groups. The role of friends in providing support varied and was predominantly based on social contact and emotional support. However, for those couples without children or close family contacts old friendships were particularly mentioned during the interview and in the network generator questions. In these cases the relationships were so established that they could rely on any sort of support and the relationship was kin-like in nature.

5.4.1 Old Friendships: *If You Need Me, No Matter, Night and Day..*

For both Cilla and Julia, who were childless, they had only included a niece and a nephew as their main family contact. However, they both talked of their long-standing friends with affection. In discussing informal support and care of Cilla's husband (Charlie), Billy an old friend was named. He had known Cilla and her husband throughout their married life (over 50 years) and continued to have regular contact with them. In this extract the support that Billy had previously given the couple alongside the promise of support in the future gave her reassurance.

JS:who gives the most positive support in terms of your caring role....?

CillaI should imagine it's Billy.

JS: Billy and that's because he's an old friend?

Cilla He's an old friend of the two of us....And he's always said if you need me, no matter, night and day.

Cilla had relied on Billy when she had been ill, and Charlie had been in intermediate care after a period of hospitalisation.

Cilla: *When Charlie was in respite...and obviously I couldn't go, Billy was there...he was with Charlie.*

JS: *That's when you were poorly, and you were in hospital...?*

Cilla: *Yeah...he used to go and...umm help and if I needed to go out, [during a later period when Cilla couldn't drive] if I needed to go and do any banking, he would especially come over*

JS: *Would he...?*

Cilla: *Yeah...take me...down to the bank...*

Later in the interview:

Cilla: *I will say when I've spoken with Billy...I said...Billy if an issue was to crop up and I was rushed into hospital...would you find it in your heart to come down...Stay with Charlie...issue his medication...I've got it all listed out...take over my role until I'm back again...he said...Cilla you don't need to ask.*

For Julia and Harry, their old friend Violet was somebody they felt they could call on for support and practical help. When Harry's movement had frozen due to the Parkinson's, and he couldn't move from his chair Violet had come to the couple's aid and managed to move Harry with the help of another friend. The couple had even considered calling her in the night when Harry had fallen out of bed.

Julia: *Well Violet helped Barry from that chair...couldn't move him...so she came and her friend as well...*

JS: *...so if you really needed some help...would Violet be the person?*

Julia: *The first...if she's at home...not on holiday...*

5.4.2 Changing Friendships: *We've dropped all our old friends*

For several carers their friendship groups had changed as the disease had progressed. A number commented on how relationships with friends and social contacts had altered and the friendship group was smaller because of the illness.

Denis offered a reflection on this in his response to the initial survey.

What the survey does not and cannot show is what social contact is lost because of Parkinson's. There are a great many things that I, we, do not do because they are relatively small and generally not noticed. [I] try not to be away from Paula for any great length of time. This kind of thing limits my opportunities to socialise. [Denis: Survey comment]

Debbie appeared acutely aware of the potentially embarrassing and stigmatising manifestations of the disease that had affected her husband. She felt that they had impacted on their long-standing friendships and did not want her husband to be embarrassed or to have to explain his deterioration. Therefore, they had formed a new network of friends associated with Parkinson's UK where Debbie felt less conscious of the effects of the disease on her husband.

Debbie: *Because of Matt's disability I don't want to put him through things that he's going to be looked at in a sort of, way. We, we've dropped all our old friends basically because umm...it's, it's, you'll be making excuses for things.*

For Henry there had been a convergence of factors that had altered the couple's friendship group. He noted how one close friend of his wife (Sandra) had become more distant and much less involved in socialising with Sandra.

Henry: *it's more...umm...people that you lose contact with...for, for whatever reason umm...,she [Sandra's friend] has become more remote as a friend I think as far as Sandra is concerned, they used to be sort of umm...see one*

another other quite often and that has for whatever reason umm...it's not as frequent.

When considering the reasons, Henry proffered.

Henry: I think umm...you, you're dealing with a woman who is the same sort of age as us, so she has grandchildren ahh...she's married, she's moved to [area] so she's doing up her house over there, but I think also the fact that umm...she may find it difficult, herself to look after Sandra, you know, she's obviously not physically in her youth, umm...ehh...so may feel that she...err is not as capable as she might have been, I don't know... maybe she feels umm unsure about looking after Sandra...I suspect that might be part of it

Henry also commented on taking over the role of organising social contact that previously his wife had undertaken and the impact that may be having on the friendship circle.

Henry: I have to be more proactive as far as ahh...friends are concerned, Sandra's friends and so forth...umm...

JS: To maintain those sort of relationship...?

Henry: To maintain the relationship. If I don't phone up, say somebody and say how are you sort of thing, get some feedback, umm...which is not a male thing you know...umm...for whatever reason, Sandra she finds it very difficult on the phone anyway. She has hearing aids and so forth so she finds it difficult to understand what people are saying, umm...so it's not something she can do particularly well...so it tends to be the onus is on me to make contact with people and say you know how about going out together etc., etc.

5.5 The Role of Community Groups and Third Sector Organisations

Involvement with local community organisations such as animal welfare groups and University of the Third Age extended the network of friends and contacts. For several carers various community groups had been long standing elements of their social

lives. All within the study had varying degrees of involvement with Parkinson's UK and some had joined other carer-related support groups. Through bridging social capital, the memberships of these groups facilitated an evolution within the informal network and for some carers this led to the development of new and increasingly close relationships that became bonded by the experiences of PD and the caring role. When comparing the interview and diary data across the 20 cases, membership of Parkinson's UK (particularly) alongside other care-related groups and the people within them became important as the disease and the care-trajectory progressed. Thus, for several of the participants these contacts became a significant source of support. In chapter six the role of TSOs in the carers' networks will be examined in depth.

5.5.1 Faith Organisations: *The Church Family*

For some carers the church was an important element of their social structure and where they gained a great deal of support for many aspects of their life and in their caring role. Adam had the largest social network, and this was dominated by his role and involvement with his church. God and his Minister were named to be called on to 'discuss important matters'. Spiritual guidance was also a support emotionally and their friends and contacts at the church meant that wide-ranging instrumental support for Adam and his wife was readily available. Gary also was regularly involved in his local church. He described their support *like a spider's web going out...* They had for many years helped Gary and the family with his eldest disabled daughter (Jane) and had helped the family purchase a suitable family car that made transport much easier. Jane had died some years previously, but members of the church (and particularly two friends from the congregation) were now providing respite support one evening per week so that Gary could attend a Pilates class.

5.6 Health and Social Care

The list of health and social care involvement varied from participant to participant. This was dependent on the severity and progression of the PD and the carer's own health needs. Private care was included in the networks of four participants. In chapter

seven the role of Health and Social Care in the carers' networks will be examined in depth.

5.7 Section Two:

The Carer's Personal Community: The Network in Action. Accessing and Utilising Resources

Across the carers' informal network in terms of their interaction with the various ties, to family and friends were a range of complex and nuanced interactions that occurred as part of everyday social life. At times greater negotiation, liaison and co-ordination was required to garner support from the network in terms of the carers' role. It became evident that there were several dynamic inter-personal factors that acted as facilitators or barriers to support for the carer. These were as follows:

- Facilitators to Support
 Reciprocity and Mutuality

- Barriers to Support
 Ambivalence, Tension and Conflict

5.7.1 Reciprocity and Mutuality

In terms of wider relationships and support the accounts from those carers with local friends and family consistently highlighted many ways that mutual and reciprocal support was provided between the carers and those close family and friends with whom they regularly interacted. The carers valued the social, emotional and instrumental support they received to assist in their caring role or in directly supporting the care-recipient. However, this was not unidirectional support and there were many incidences where carers highlighted their role in the on-going support of their families and friends. Thus, supportive exchanges were evident across the generations. Children were the main beneficiaries of support from the carer (and the care-recipient). Carers continued to offer instrumental support although this was more limited because of their role commitments. However, several discussed the financial support given to their children and stepchildren (Margaret and Elizabeth) and Lenny discussed the financial support

he gave to his brother overseas. Each of the carers who had grandchildren close by discussed their role in caring for them as a support to their own children and the mutual pleasure that this provided.

Debbie and Tom both had grandchildren living with them. Despite their caring responsibilities they both continued to be closely involved.

Debbie: Nicola [daughter] has asked me if I can have Charlie one Friday coming up soon, she's, it's Eva's nursery school outing to [Theme Park]... And I said yes and then we got a letter saying that Matt's got an appointment with the speech and language therapist at [hospital] that day, so I think I might even ask them to pick him up, they can arrange transport...: Umm but I, I'll wait and I'll speak to Nicola about it but coz it would be a shame, I'd love to have Charlie for the day...he, he, he's its...we could get up to all sorts, he and I go to Costa Coffee...

Tom discussed his daughters return to the family home ten years ago after her divorce and the diagnosis of PD for his wife. In the interview he discussed his (and his wife's) involvement in caring for their grandson:

Tom: We [Tom and his wife] were alone for 10 years and so you, you know we just did what we like when we like and suddenly, they came back and there was a little 7 year old...so we stopped doing what we liked when we liked because [daughter] went to work...and so we had the caring role for him as well...

JS: Oh ...so did you do the school run and things like that...

Tom: Oh yeah...

JS: You've been heavily involved in bringing your grandson up...?

Tom: Absolutely oh yes, yeah, yeah, I mean we used to go and meet him from school...yeah he wanted me to be a dad, I said no I can't, I said I want to be a grandfather, not, I can't be a dad and so it's...

JS: Oh but he's going to have a very close relationship with you both...

Tom: *Oh yes we get on well together...Go cycling together, oh it's wonderful...it really is, of course that's less and less now he's 17. It's fine, no its wonderful...*

Tom also discussed his relationship with a neighbour of many years (Brian) who was a very close friend and, as an octogenarian, beginning to need support himself. He too had cared for his own wife for some years until her death and had been a long-standing source of advice for Tom. To help Brian, Tom now did his shopping and was prepared to offer any other assistance that he might need.

Gerald was emotionally close to all three of his children. His daughter Anna had been born with a significant physical disability and was wheelchair bound She lived close to her parents with her husband. Occasionally when her husband was not available Gerald helped to wash her hair. He reflected on the care she had needed as a child and her own experiences of ill-health. He was proud of her ability to help him and others with advice because of her own experiences.

Gerald: *...but I can almost ask her anything and umm, she would have some input, because her, own physical experience of, all different sorts and umm, she's, she's almost like a counsellor... and you know and she always has input into people's lives... ...she's, she's amazing, she's not had any training in that, but she just has, she has insight...*

JS: *Ok and is that because of her own condition...*

Gerald: *Her own experience with hospitals, doctors, local council.*

Within these accounts, it is evident that the carers were tied interdependently with those in their informal network of family and friends. Thus, the carer and care-recipient had relationships that were not solely one of dependence on others but involved mutual assistance and support which was an integral part of their relationships with family and friends.

5.7.2 Ambivalence, Tensions and Conflict

In exploring the relational dynamics associated with the carers interaction it became apparent that the carers had at times contradictory emotions and thoughts about those within the informal network. Such ambivalence also gave rise to conflicts and tensions within the network and these aspects of interpersonal relationships were evident between the carer and other family members and across the wider informal network. Often the source of the tension or conflict appeared to be associated with a failure to recognise or understand and appreciate the carer's role. This was further heightened when support or assistance was perceived as lacking or unavailable. Several factors appeared to intersect that generated the individual's sense of ambivalence. Thus, the personal biography of the carer and the timing of the care episode were situated in a unique personal social and cultural context. These factors all impacted on the complex relationships that existed across the informal network. At times the carer appeared caught in negotiating the juxtaposition of their ambivalence, the conflict, and tensions that arose and the support required to manage and co-ordinate care.

The following three vignettes illuminate how the carers' personal biographies alongside the social and cultural contexts of care all gave rise to ambivalent relationships with the associated conflict and tensions.

Elizabeth and her Stepdaughter: *She can't be what I want her to be*

In the interview Elizabeth described the relationship with her stepchildren at length and especially her relationship with the middle stepdaughter Lydia.

Elizabeth: ...I used to be so close to the younger one [daughter], Lydia.....This is the biggest disappointment but I honestly think...I've come to the conclusion she can't cope with disability...she finds it really difficult...you know so to see her Father not as she remembers him but you know as...I don't think she can cope...umm and I honestly think in all the time he's been going downhill...I can't think she ever says what can I do for you...?

This perceived lack of support for Elizabeth was further heightened by Lydia's planned charitable activity in support of Cure for Parkinson's.

Elizabeth: *...and I'm thinking well Lydia it's all very well doing this for all these unknown Parkinson people...you know...what are you doing for your father...*

Later in the interview Elizabeth had discussed giving a substantial amount of money directly to Lydia's children. However, Elizabeth believed this had added to the deterioration in their relationship.

Elizabeth: *You just don't know...she is a control freak...maybe she didn't like the fact that we gave money directly to her children...rather than to her... So, she's been a great disappointment and it's not going to change and Charles [Elizabeth's brother] is very good at sort of saying yes well, don't worry, she can't change its her nature...and she can't...she can't be what I want her to be.*

However, there was evidence of Lydia's support to her father and Elizabeth in the diary entries. Elizabeth's responses (both positive and negative) were captured in several diary accounts.

[Lydia] Kindly came to collect me after anaesthetic at dentist whilst Charles [Elizabeth's brother] looked after Mark. Had made a cake for her father but didn't come in for 5 minutes to say hello to him. It does make me angry as Mark had been wretched that morning and I had made SOS calls to neurologist and private GP asking for meeting.

[Lydia] Called to suggest when she comes tomorrow, she wheels Mark in his wheelchair to the café in the middle of [name of park]. Kind thought.

[Elizabeth: Diary Extracts]

Dawit: The Interplay of Family, Social Expectation and Culture

Dawit had a range of individuals within his network from both his own and his wife's family. They had originated from North Africa and with family members they belonged to an informal network of friends from the same country. The members of this group met regularly. The group supported each other in many varied ways. Previously they had been a great source of support for Dawit and his wife when caring for their severely disabled son who had subsequently died. Thus, the group's normative expectations

and cultural practices were widely shared and understood by its members. However, at times, this was difficult for him as he stated in the interview.

Dawit: To be honest I'm not short of people who volunteer, it is me who does not want it , I say its ok...because...at times I find that [the help] more pressuring.

For Dawit, the constraints on his time were significant and there was a sense that this was not understood by those around him. The following diary entry captures the tension and conflict felt by him.

[Sister in law] says that there are people (related to Zara) who want to come and visit her. I had told to some of these people that Zara was not well, and it is not the right time to visit her and that I would be in touch when she gets better. They now have spoken to Zara saying that they would like to visit her and that I had not got back to them. I also discussed this with Zara as it is causing a little bit of tension! I am not keen for people to come and visit her as they stay for almost all day – which is a cultural thing to do but that puts pressure on Zara and me!.I mind because it takes a lot of my precious time to entertain guests – when I have a lot of things to do!On reflection this is an interplay of family – social expectations/ cultural / custom etc when living in a modern fast living society!

[Dawit: Diary Extract]

Mary: *The day that I lose my Mum that's the day I cut ties with them completely*

The following extract discusses Mary's maternal family (based in the EU) who over the years had made little effort to support Mary or her mother. There had been no contact recently despite knowing that Mary's mother had been ill, since it meant that they had to cancel their travel abroad to a family wedding.

Mary: Umm, they're all in [country], no nobody's here.....they didn't give a damn, but I'm used to that, coz that's what they do, you know, they don't, none of them bothered...to, to think, I had to phone them up and obviously say we can't come

to the wedding.....they never rang up to say how she was...or anything like that, ring me, ask me how I am, nothing...

In the past Mary's mother had also cared for other family members when they had been sick, but Mary felt that this care was not being reciprocated for her other, despite her need. It was apparent that managing the relationship with her maternal family was complex since Mary felt that she must maintain contact for her mother's sake, and she was conscious of her mother's thoughts and feelings on the matter. Thus, there was a difficult balance of managing the relationship while her mother was alive and yet feeling angry that they did not recognise her needs or fears.

JS:does she [Mary's mother] ever, sort of feel that they're not very supportive...

Mary: She knows they're not...but....my Mum's biggest fear is that when she passes is I've got no-one, so in her mind she's thinking...well...even if they're crap, (laughs) it's better that they're in my life...but I've said to her...no when...the day that I lose my Mum that's the day I cut ties with them completely because..... well they've not done anything for me while she's alive.

Later in the interview.

Mary: Yeah, you know...and when my Mum's Mother was ill...saying that my Mum would go over and take turns...I mean Mum was having to pay for those fares...on her own, she didn't have a husband or anyone else to do it, you know...but...they make me sick, that's why I can't wait for the day that I don't have to ever have anything to do with them...but its bitter sweet because it's the time that I don't have, my Mum, whose the most important person to me, you know and the only person who does actually care about my feelings and what have you, so...yeah...difficult...

Each of these accounts demonstrates the complexities of the relationships within the network with the relational dynamics evolving as the situation unfolds. Each relationship is inter-dependent, and the carer's position means that they must

negotiate their relationships not only on their own behalf but also cognisant of the care-recipient's thoughts, feelings, and needs.

5.8 Accessing and Utilising Resources: The Carer as a Network Bridge, Network Broker, and Network Co-ordinator

In their role, it was evident that the carers' personal resources and attributes were instrumental in shaping and coordinating the network, that formed their personal community. Several of the carers were particularly active in developing and extending their network in support of their caring role. The links made with Parkinson's UK and other TSO's were a feature of this. In this bridging role the relationships that subsequently developed with these organisations led to an increase in the carers' informal network and offered access for the carer and care-recipient to a range of resources. Although all were involved with Parkinson's UK in some capacity, others had also accessed other carer associated groups that were also being utilised as sources of knowledge, and friendship. For several carers the friendships that developed brought both social and emotional support and at times instrumental support. The nature of the carers' involvement with these organisations and the potential benefits and impact on the carer will be discussed in greater detail in chapter six. However, to illustrate the extent to which involvement in these organisations can impact and shape the carer's informal network, Carly will be presented as a vignette.

5.8.1 Extending the Network of Support: *They play a very big part in our life...*

In our daily life

This statement is a quote from Carly that was stated in the first ten minutes of our second interview, when asked about the significant number of individuals from the Parkinson's UK groups who were named in the network generator questions, and her diary data. A sociogram is presented for Carly (see Figure 7) that illustrates the extent of this group in Carly's informal network. Carly was an outgoing, sociable individual and as migrants neither herself nor Robert, her husband, had family in the UK. The network data and interview demonstrated how pro-active she was in developing, extending, and shaping her network of friends. These had been established locally (particularly her neighbours who were classed as friends) and included members of

the Parkinson's UK groups. To achieve this range of membership and activity with Parkinson's UK and a local carer-related organisation, had involved complex navigation. Initially the online contact offered an entry point which moved to attending different groups and activities and finding those that were most beneficial to her and Robert. From the account, it was striking how integral these friendships had become in Carly's network. As her and Robert's involvement and commitment to the groups evolved, they had developed intense closely-knit friendships that were important socially but also offered empathic, emotional support.

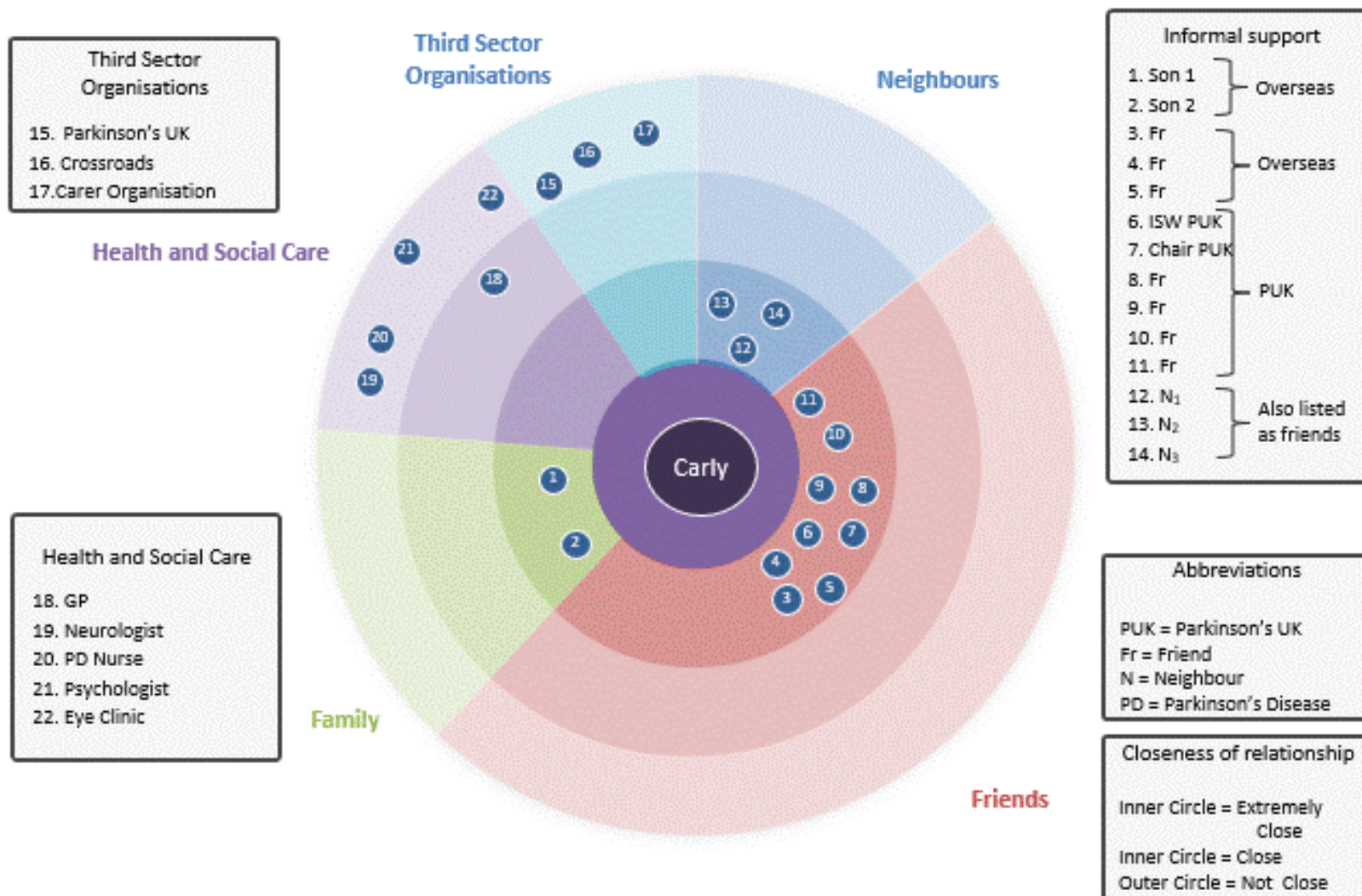
Carly: ...it was clear that umm, the people at these groups were very umm, welcoming,...umm, very supportive and very eager, eh, to socialise and umm.... you know form a nice bond with you and all that sort of thing and, and very, very, gradually Robert opened up completely with these people and in the end he was just chatting like they were, ...well what medication do you take,...do you find its a benefit,...and how long have you been coming to the support group...and what have you gained from it, all those sort of things....

5.8.2 Identifying Resources: *Who can do what for you*

In organising support and assistance with care some carers often acted as a co-ordinator and would seek to involve members of the personal community. Within, this role the carer was often acting to manage caring contingencies and to actively recruit support and assistance. This took place in the context of the relationships of the individuals involved and their individual circumstances. This negotiation was nuanced and at times a detailed process. It was determined by several inter-related factors, which could facilitate or constrain access to support. These included the relationship of the individual with the carer and care-recipient, their availability and propensity for support and the nature of support that might be required.

In her interview, Monica discussed her recent negotiations with her brother to provide some respite for her by looking after their father for a few days. As described earlier (section 5.3.9), her brother had little involvement in caring for their father

Figure 7: Extending the Network of Support- Carly



However, Monica had decided that the timing and opportunity was now right since her brother had recently retired and his family were grown up. She was also conscious of her father's limited lifespan, and wanted them to spend time together since her brother had not seen their father's deterioration and increasing frailty

Monica: I think we're going into a different phase at the moment erm...and it's about the balance...coz I...I think it will come where perhaps the length of time I go out for will be shorter.

She therefore needed some respite and had been advised by her own GP to take a break. Monica's brother had agreed, and she had organised for her cousin (also medically trained), and a good friend, to visit to support her brother while she was away. She hoped that this preliminary arrangement might lead to more regular involvement by her brother.

*Monica: ... but I must say my brother is coming up trumps now..... I was hoping to go to Ireland for a few days umm...and I said, Jack a favour would you be able to come and err, stay and he said, yes...I hope he will come the night before and I can talk him through the routine and pills and things, which is so easy for me, but for someone stepping in...
...and so it will be very interesting to see how the two of them get on ...he's very, very logical, very meticulous (laughs), but I think it will do them...you know good,as my Father is deteriorating I would hate it that he hadn't seen him before he died...*

Later in the interview:

I'll see how it works with my brother because umm...I see it could work, if, if he, if it really works well, then I could see sort of, if he came every two months or something and did a four night stay.

At the interview, Debbie recounted the difficulties she had encountered given her husband's recent hospitalisation and return home. Debbie had decided she needed some respite and had decided to enlist the support of three of her four children. She

had booked a short cruise and her older daughter had offered to accompany her whilst the younger daughter and her son were enlisted to care for their father.

Debbie: *I just went through [a magazine] and it just said 3 day cruise from Tilbury, Amsterdam and Antwerp and I thought ahh...:I could do that, so I spoke to Nicola [youngest daughter] and she said she'll look after Dad on the Thursday and Friday and I spoke to [oldest son] and he's going to come and stay for the Saturday and Sunday...*

JS: *Ok...*

Debbie: *We'll be back by lunchtime Sunday I expect*

JS: *Right OK so it's not too long is it...?*

Debbie: *It's not, it's not too much to ask any of them*

Her sister-in-law had also offered to visit her brother to care for him and Debbie was now planning to utilise this opportunity to organise a further two-night stay in a hotel.

Debbie: *Well oh it, it's really quite funny because [sister in law] said she could do the first weekend in August or the second weekend or it might be a bit later in September but...the cruise is the 3rd of September...*

JS: *Has she done that for you before, did Marion come and stay before is that right...*

Debbie: *She came when I had my knee done last year...*

Certain friends were also identified for their kindness and attentiveness. In these interview and diary excerpts Elizabeth highlighted a close friend who could be relied on for support and could always be asked to help.

Elizabeth *She's [close friend] one of the people...she is the...she's my most useful person...*

JS: *Ok...what would Sally do...is she a great confidante...?*

Elizabeth: *For example...she's very, very practical...when we first moved into the flat...she would come on Saturday mornings, and she would bring a picnic lunch for us...umm when Mark was in the [name of hospital] recently...I think*

three times...she said no arguments...I'm picking you up at half past 6 and I'm taking you out for supper...

[Sally] Rang to touch base after her holiday, check up on how we both were. After my brother, my most supportive friend. Going to take us out to lunch soon.

Elizabeth: [Diary Extract]

To draw on such resources within the network, there needed to be a range of individuals within the informal group that could be accessed, had the required skills and resources and were willing to offer and provide support. It also required the carer to seek and request support. Thus, for those with the smallest networks such as Mary there was less opportunity to do this. As an only-child isolated from her wider family, she had developed her own independence. Here in her interview, she considers why she may not ask for support despite the potential help that somebody like the Parkinson's UK Information and Support Worker (ISW) might offer.

Mary: I think it's one of those things, because I've been so used to having to deal with things on my own, that I forget that these people are there to help, you know, I just kind of...I just used to like sort of...closing ranks within myself and just try and get on with it and deal with what's going on, and no he was really good and when my mum had the TIA you know, he [ISW] was the first person to come up and say...how are you...?Yeah and that was kind of quite...a shock for me you know, and umm...he was sort of saying look you know is there anything that you need, do you think your Mum needs umm dial a ride or anything like that...?...So yeah he was sort of there straight away...

Mary was also cognisant of the personal position of her close friend (Lana, who she had listed as somebody who might support her in her caring role). This also affected her decisions about possible contact if she needed support.

Mary: She (Lana) has, I mean when my Mum was taken to hospital, she said, is there anything that you need? You know kind of let me know. She's a single parent herself so she's kind of ...it's one of those things where I wouldn't kind of

necessarily ask her because she's dealing with stuff herself you know, so it's not like I can call her in the middle of the night and go, can you come over?Or help...or whatever so...again it's those things where I tend to deal with it on my own...

To access resources within their network these carers negotiated with individuals across their informal network. This was contextually dependent with careful consideration of relationships within the network not only with the carer but also the care-recipient and others. In exercising agency to shape the network and harness support, the historical and cultural context of the carers' relationships impacted on the support provided. Inherent reciprocity and mutuality within the personal community enabled carer support and was a feature of those ties with close-kin and old friends. However, ambivalence in relationships, and associated conflict and tensions was also a feature. Thus, the carer also needed to navigate more complex scenarios and situations as part of their role.

5.9 Summary

In this chapter the composition shape, dynamism and utility of the carer's' was examined through the lens of their 'Personal Community'. The form, function, and associations of those in the personal community were considered in terms of carer support and the impact on the caring role. This approach offered a structural and relational perspective that uncovered a complex web of relationship. The networks were heterogeneous, exhibited fluidity and were shaped by demographic factors and intricate relational dynamics that formed part of the on-going carer's personal biography. Migration and the dispersal of families that is a feature of modern life impacted on the availability of support. However, several carers were actively using electronic means to maintain contact with distant family and friends, allowing for on-going social contact and a means of emotional support. Those that the carer was most likely to turn to in support of their caring role confirmed a gender bias as across the participants the carers were more likely to call on female family (especially daughters) and friends for emotional and instrumental support in their caring role. The role of bonding social capital was evident through mutuality and reciprocity, as family and

friends coalesced and provided social, emotional, and instrumental support. The data uncovered stable, long-standing networks alongside newer and evolving ties that had developed in response to the individual circumstances and biographies of the carer, the care-recipient and those inter-related with the dyad. For many of the carers, kin were prominent in providing regular instrumental and emotional support to the carer to assist in their role and in directly supporting the care-recipient. However, both old and new friendships were important for many and these certainly offered both perceived and received support. For some, the development of close friendships was driven by migration and geography and were also a product of the carer and care recipient's involvement with TSOs associated with the PD diagnosis. The inter-play of the caring role with the changing demands of care along the care trajectory influenced the on-going social interactions with family and friends. Thus, a sense of dynamism and change was apparent as carers negotiated support and shaped the network through reflexively responding to the demands placed upon them.

Across the personal community nuanced and bespoke exchanges took place many of which were viewed as beneficial in the caring role. However, other acts or omissions were viewed by carers as unhelpful or at times detrimental to the carer and their role. Ambivalence was evident in some of the parent-child and step relationships which resulted in conflict and tension around care provision. Such ambivalence was not only a feature of close-kin relationships but also extended to the wider family and friends. Long standing historical features of the relationship including the cultural context of the care giving situation also contributed to this. These feelings of ambivalence appeared to be compounded by a lack of recognition of the carer's role, and disappointment in the support and understanding provided. For some, personal biographies resulted in smaller networks with limited access to support and this was exacerbated by long-standing conflict and tensions.

In developing and extending the network bridging social capital through TSOs enabled links to form with alters beyond the established informal network. For some, these replaced or supplemented existing friendships and offered insightful carer support and understanding. From many carers' accounts, their agency in co-ordinating and bridging the network to enable and manage the care provided was evident. This demanded negotiation that also required navigation and harnessing of those individual resources available to the carer. Thus, the carer drew on various personal resources

of which their social network was one aspect but also included finance and individual attributes or human capital through their education, knowledge, skills and experience.

Chapter 6: Results

Third Sector Organisations: Bridging and Connecting.

A whole new world has opened to us.

6.1 Introduction

In the second of the results chapters the wider contributions of Third Sector Organisations (TSOs) in the context of caregiving and particularly in relation to the role of the carer will be explored. Thus, the emphasis will now move from those elements that are most closely associated with informal care that is friends, family, and neighbours alongside their associated bonding social capital to those networks that have been developed at a community level. The concept of bridging social capital will be considered in relation to these community-level connections between the carer, care-recipient, and the Third Sector organisations (TSOs). In examining this aspect of the network Cantor's model (1979, 1991) was useful in considering this structural level of support. As in chapter five the following research questions will be examined to further delineate the carers' networks and their impact on the carers' role.

- What are the forms, functions, and associations of carers' social networks?
- How do carers access and utilise the resources contained within these networks?

The chapter will also address the following:

- What role do the health and social care sectors and the local community have in shaping or developing carers' social networks?

In determining those organisations that do not incorporate the formal health and social care sectors, the following definition was used to identify those named in the network generators and interviews as belonging to this sector and having relevance to the carer's social network

Third sector organisation is a term used to describe the range of organisations that are neither public sector nor private sector. It includes voluntary and

community organisations (both registered charities and other organisations such as associations, self-help groups and community groups), social enterprises, mutuals and co-operatives (National Audit Office, 2013)

In examining the data related to those organisations most directly involved in the carer's role several themes and subthemes became apparent. These are outlined in Table 15. Each of the key themes will now be presented. The diary and interview extracts from many of the participants will be used to illustrate the form, dynamics, and outcome of this network on the carer and its impact on the caring role.

6.2 The Range of Third Sector Organisations Accessed

The name generator data and interviews uncovered a multitude of TSOs that were utilised directly by the carer or indirectly via the care recipient. Table 16 contains a list of those identified for each carer. Those directly related to the caring role or related to the care-recipients illness are named in full. Those of a more general nature are grouped as hobby/general interest and will not be specifically referred to in the following discussions. A range of TSOs were evident across the carers who participated. All the participants were recruited via Parkinson's UK. Thus, membership of that organisation and associated Parkinson's related groups and activities are therefore especially prominent.

6.3 Group Entry: Negotiation and Navigation

To examine the sub-theme, Group Entry, Parkinson's UK will be predominantly discussed since all the carers and the care-recipients had some level of involvement. However, access to other organisations will also be highlighted to further develop this section. To access these groups the carer (and care-recipient) navigated a path to the support that these organisations might offer. Furthermore, as carers engaged with and participated in these groups' negotiation was apparent with the care-recipient to agree the timing of entry and level of participation.

Table 15: Third Sector Organisations: Concepts, Themes and Subthemes

Over-Arching Concept	Theme	Sub-theme	Key Elements
<p>Third Sector Organisations (TSOs): Bridging and Connecting</p> <p><i>A whole new world has opened up to us</i></p>	<p>The Range of TSOs Accessed</p> <p>Building Bridges to Shape the Network</p>	<p>Group Entry: Negotiation and Navigation</p>	<p><u>Intrinsic Factors</u></p> <p>Fear and stigma</p> <p>Sociability</p> <p>Carer and care-recipient 'needs'</p> <p><u>Extrinsic Factors</u></p> <p>Group attributes (bonds and connections)</p> <p>Locality and accessibility</p> <p>Helplines and on-line presence</p> <p>Carers as a network bridge: Introductions and opening doors</p>
	<p><i>A Lifeline</i></p> <p>The Network in Action: Accessing and Utilising Resources</p>	<p>Carer Well-being</p>	<p>Cognitive and physical well-being</p> <ul style="list-style-type: none"> • Events, classes, outings and holidays • Respite and restoration • Personal and vicarious enjoyment <p>Self-esteem</p> <ul style="list-style-type: none"> • Utilising and developing skills <p>Social Companionship: <i>Wonderful support groups...wonderful friendships so much happiness</i></p>
		<p>Support with Illness Work</p>	<p>Developing knowledge and skills</p> <ul style="list-style-type: none"> • ISW and 'Go to' people (network bridges) • Health Professional Contact • The Group: <i>Everybody was sharing and everybody was quite willing to listen to everybody else share</i>

Table 16: Carer Involvement with Third Sector Organisations

Carer	Parkinson's UK	PD Dance*	PD Singing	PD Bowls/Games*	PD Yoga*	Carer Group	Cross-roads*	Dementia Group	Age UK	Luncheon Club/Day centre*	Demand	**Hobbies and Interests Groups
Carly	•	•				•	•					•
Cilla	•							•		•		•
Mary	•	•			•	•			•	•		
Elizabeth	•		•									
Julia	•	•	•			•						•
Harriet	•											••••
Margaret	•	•										••
Susan	•	•										
Monica	•	•										
Adam	•	•										
Lenny	•	•										
Dawit	•											
Henry	•	•										•
Caroline	•			•								
Debbie	•			•				•		•		
Gerald	•											
Tom	•			•		•	•				•	
Denis	•											•
Maureen	•			•								•
Gary	•					•	•	•				•

*Utilised by some carers for ad-hoc or planned respite**Hobbies and Interest Groups Included: WI; Trefoil; Animal Rescue; Local Bowls; Golf, Local Meet Up, Volunteering, Historical, U3A, Keep Fit

6.3.1 Intrinsic and Extrinsic Factors Affecting Entry

Entry to the organisation was often determined by the care recipient. However, in some cases the carer made the first contact. Both intrinsic and extrinsic factors determined entry and participation with the groups. For both the carer and care-recipient, intrinsic factors such as readiness to join and overcoming fear and stigma were important. The carer's needs in terms of their decision to become involved alongside the acknowledgement of the mutual needs of the dyad were factors that required negotiation regarding solo or joint participation and engagement with the groups. Personal sociability was another individual factor that impacted on participation. Extrinsic factors were related to the ambience of the group, locality and accessibility and factors that aided entry such as exposure via an online presence or through personal introductions.

6.3.2 Intrinsic Factors

Fear and Stigma: ...she didn't want to go...because she didn't want to see what she was in for later on

Stigma and fear for the future was discussed by several of the carers as they recalled the early period of diagnosis and involvement with Parkinson's UK. The associated disability and the outward physical changes seen in neurological conditions such as PD (Caap-Ahlgren et al., 2002; Gibson & Kierans, 2017; Hermanns, 2013; Pinder, 1992; Solimeo, 2008) gave the care-recipients and carers an initial reluctance to attend and participate in the local groups.

Adam who was caring for his wife (diagnosed in her 50s) recounted her hesitancy about joining the groups.

Adam: Julie was diagnosed in 2005. We had no contact with other groups for 2 years. I then went. Julie sent me...to the support group. She'd heard of the support group, but she didn't want to go...because she didn't want to see what she was in for later on...umm there were probably other reasons as well. Anyway, I went...It was being led by an ex colleague of mine from [name of work] and they were a nice group of people. I came back and I said, well, they were a very pleasant group of people and you'd get on with them alright. Then she thought they are only people after all, and she went and ...so that would

have been...6 years ago...and she, she started going to the support group and eventually found she was asked to lead it...and she took over leadership.

For Margaret and her husband, the notion and thought of disability was difficult as this extract conveys

JS: Ok...so you didn't join...you didn't join the Parkinson group early on when Jim was first diagnosed or anything...?

Margaret: No...we didn't want anything to do with Parkinson's.

JS: Right ok...why was that?

Margaret: I don't know...I suppose because it's...I think, kind of its ageing and umm...I, I can't bear anything that's disabled. Jim won't have a stair lift...he won't have any help in the bath...we've got a huge deep bath...and he won't...won't have a handle or anything put in...he said no I don't want anything that reminds me of disabled.

Harriet was in the early stages of acquiring the carer role and when asked about her and her husband's involvement commented as follows:

Harriet: I think it's something that we will take up when things get more difficult...it's too early yet...

Later in the interview there was acknowledgement of the potential benefits for her husband, but her own fear and worries were expressed about what the future might hold for somebody with the disease.

Harriet: Right...we go to their monthly meetings and we sometimes go to other things that they do...and Bill goes to the singing group...and umm...he's met several people through the singing group and through Parkinson's generally and I think it helps to know people who...who have Parkinson's ...but it's a bit...a bit...daunting when you see how some of them are reacting...they've had it for several years...the degree...the disease has progressed quite a bit...I think it's rather worrying sometimes.

At the time of the study, Harriet was one of two carers (including Dawit) whose involvement with Parkinson's UK was more limited than other carers in the study. Harriet was at the beginning of her carer career (Nolan, 1996; Aneshensel, 1995) and didn't appear ready to become involved commenting *it's too early yet*. This participant was also very busy with her own personal hobbies and interests (as noted in Table 16). On commenting on some members' involvement in the group she stated, *it becomes their life really doesn't it. I think we will try to avoid it becoming our life*. Given that this carer had expressed her own worries and fears for the future, this comment was maybe a desire that her husband's condition would remain stable, and the changes and deterioration associated with the illness would not become their future life.

Sociability

During the interview with Dawit, it became apparent, that time pressures associated with his caring role meant he found it personally difficult to take the time to attend these classes. Although he was interested in getting information about the disease and its associated therapies (he had accessed on-line information with his wife) and he had attended medical talks at the group, the contact with the group was mainly via his wife. He appeared not to want to actively seek out social opportunities. He used the time while his wife attended the group to carry out the grocery shopping or general household chores.

Carer and Care- Recipient Needs

Mary's account was interesting and offered a detailed view of how entry to Parkinson's UK was navigated which then facilitated access to other groups beyond. As an only adult child, Mary was the sole carer for her divorced mother. As presented in chapter five Mary's social network was limited but identified within it are several significant alters associated with the Parkinson's UK group. Early after diagnosis Mary's mother had several difficult and worrying side-effects due to the medication and Mary was eager to find out more information. In this account, her first exposure to a Parkinson's related group was via an on-line forum which proved to be a negative experience, although subsequently access via another site proved to be more positive.

Mary..... when I first went onto the forums...

JS: Yeah and that was before your mother joined the group wasn't it...?

Mary ...yeah that was quite interesting coz that's effectively people who've got Parkinson's and I suppose their carers or whatever..... I needed to understand the condition myself...and also the fact that my mum was so ill on the medication... ..I wanted to know how other people coped with the medication.

JS: Other side effects and things ...

Mary And umm...yes sort of introduced myself as...you know...my names [name], a carer for my mother, she has Parkinson'sand then I got vilified for using the word carer, and that was like, a woman on it that said that umm....., nobody's a carer here,[Mary then wrote online] I'm her daughter, you know and the word to me, carer is because I care deeply about her and I care for her, you know, I care about her welfare...and umm...like this whole debate came up you know, with other people going...yeah you shouldn't use that word,this one guy just come piping up and saying,can you just you know stop, coz she came on here for help, for a reasonlet's help [name], lets actually welcome her...and he was really nice but I think, I only went on it [the site], once after that,....I was also on a different American site

JS: You did mention that.

Mary: They were fantastic, they were so lovely and umm, I actually found more comfort in them...than the, the, [other] site, and they were really good about the medications and stuff and explained to me, oh you know, welcome, you know, you know it's a hard road ahead, we don't want to lie to you about that, and stuff, which I thought was quite nice to have somebody saying that, you know, umm but we're all here to support you and sort of, they were explaining about medications that people they were looking after were on, or that they were on themselves, and umm...what to avoid.

Later in the interview, Mary discussed how through persuasion and known contacts her Mother had finally gone to the regular Parkinson's UK group. This excerpt also illustrates the dynamism of the network over time and place and demonstrates how the care-recipient and carer negotiated their participation. Crucially, as time elapsed following the diagnosis, Mary's mother, with encouragement from her daughter and a

Parkinson's UK contact, became psychologically prepared for more involvement in the groups.

Mary: *I found out about, us going to that group, the umm Parkinson's UK group, when my mum was first diagnosed. [As] I said, I went onto different forums and stuff like that and I said look there's a support group in [X] Town. My mum didn't want to know and I was like, please mum we need to speak to people, we need to kind of understand, but, what a lot of people when they get like a diagnosis like that they go on kind of a downward spiral until its, they can kind of accept it and then they kind of start building up. She didn't want to know about it, none of that and then as time went on we found out about the, umm, there was a yoga class for Parkinson's people,..... yeah, so my mum goes ...anyway there was that and then we found out about the movement for Parkinson's ...umm, in [X] so my Mum started to go there, that's when she met Joan...*

JS: *Ahh ok, before the [named Parkinson's UK] group...*

Mary: *Yeah so I'd said to my mother about this [named Parkinson's UK] group and she didn't want to know. So about a good year later, must be...she goes to [named] group, meets Joan. Joan oh you must, come, there's a support group in [X] ...all of a sudden my Mum's like, there's a support group. I went, I know, that's the one I've been trying to get you to come to. So she goes oh well I might go then...*

JS: *What do you think it was for your mum, just getting used to the diagnosis...?*

Mary: *Partly that but I think what helped was her seeing other people with the condition...that were coping with the condition...*

JS: *A positive image...?...*

Mary: *Yeah, I think everything has to have a positive image.*

Interestingly, like Mary, Caroline was an adult daughter caring for her widowed father. In this case he had heard about the group through the Parkinson's nurse and when he had finally attended, he met an ex-colleague that also facilitated his access to the group. In this case, Caroline's Father had then been the one to encourage his daughter to join and attend the daytime group with him. This was possible since she had been made unemployed not that long before.

Carolineand he [her father] said to me you should come along...and err I said yeah but I feel like I'm encroaching on your time...and he said oh no they're really friendly and that. So I went, and they just with...with open arms, they welcome you with open arms,

Highlighted in both scenarios, is the nuanced communication within the care dyad regarding their involvement and entry to the groups. As the child became the prime carer, there was a change in the nature of the child-parent relationship. As the relationship alters there is a transition in the perception by both parties in relation to the parent's independence. This shift in roles can be gradual in a slow-onset disease such as PD with what were defined roles and boundaries being renegotiated over time as there are changes in dependency between the carer and care-recipient and particularly in these cases, the child-parent relationship (Finch and Mason, 1993). Mary's mother appeared to be initially resisting her daughter's ideas about the group and exerting her own autonomy, whereas for Caroline she was still conscious that her father potentially needed to be independent, managing his own time and space separate to her.

For Gary, a period of depression and the increasing demands of the carer role had led him to consider his own needs and to maximise his opportunities for social engagement, while his wife was receiving day-care. It was evident that he had consciously decided to become involved in a range of carer specific groups. For him, these understood his caring role and offered an escape from his caring duties.

Gary: *Well, these groups I've got in contact with have only come about gradually, I've contacted one and gone to one group and started doing...going to carers cafes or something...*

JS: *Yeah...*

Gary: *And then you know a year later I found another group and then gone to something else as well, its gradually built up... Been on one or two conferences and they've suggested things, I thought I'll try it you know, so I go along with trepidation (laughs), another group, new people...*

These excerpts also clearly illustrate how, over time, individuals begin to navigate across the network and how this widens access and opportunities as their contacts and interactions increase.

6.3.3 Extrinsic Factors

Several extrinsic factors that influenced participation were also identified in the data. These included locality and accessibility, the attributes of the group, the organisation's on-line presence and helpline access. Having an introduction to the group by friends and acquaintances or having an inside contact also facilitated entry. As described in Mary's case the on-line presence of Parkinson's UK and other PD organisations certainly facilitated subsequent entry to the local groups. On-line access was often early in the course of the disease and the caregiver trajectory and directly related to the carer or care recipient's need for information about the disease and the medication. The telephone helpline was also accessed by Carly early in the diagnosis she was finding dealing with the illness difficult. She had felt limited in who she could discuss the illness with, since the diagnosis was kept secret for some time because it could have affected her husband's ability to get work as a musician. This approach therefore offered anonymity as well as support and advice.

Group Attributes

On making contact and becoming more involved with Parkinson's UK and other organisations the overall experience was invariably positive and many commented affectionately or with praise about the groups they were participating in. Although the groups had heterogeneity in terms of social and cultural backgrounds there was a group homophily in relation to the PD diagnosis or being a carer. This 'bond' or 'connection' helped to create a conducive atmosphere and was certainly a factor in joining and engaging with the Parkinson's and carer groups. In discussing the PD dance group Carly made the following comment.

Carly: ...it's just, its people from all walks of life err and everybody very, very swiftly develops a very easy rapport with each other, umm I've never come across a group like this actually, it's really quite amazing I mean I know you have the bond with this disability...

Gary (a quiet and reserved man) was finding a local carers' group very beneficial in terms of discussing his own personal experiences. This shared understanding he found with the group was articulated as follows:

Gary: Umm...I'm not very outgoing but having a connection kind of helps you to...share and talk to each other if you know what I mean...

Unfortunately, where initial contact with an organisation was difficult that could leave a negative impression and upset for the carer as described in Tom's diary.

Tom: Invited via internet talk by [a third-party organisation]. Tea and cake. When I arrived with my wife told by another carer, carers only. My wife not welcome. After speaking to lady from [name of carers group] ...we left very upset and hurt.

[Tom Diary Extract]

This took place a short time before the main interview and Tom was still angry by the incident when we met. This had been his first main visit to this carer's group, and he had been keen to assess what they might have to offer. His wife was severely disabled by her condition, and it was not possible to leave her alone at home. As such it had taken him time to get her ready and to the event. At the interview, this incident had come at a particularly difficult time for Tom in his caring role and had certainly added to his frustrations during that period.

Carers as a Network Bridge: Introductions and Opening Doors

As was illustrated in Mary, Adam's, and Caroline's extracts above, acquaintances and contacts also played a role in the entry of these carers and the care-recipients into Parkinson's UK. As described in the methodology chapter (section 3.8) it was apparent that Mary through her involvement with the Parkinson's UK group and the wider carer network had herself become a bridging tie and was enabling introductions and opening doors for others. This was demonstrated when at a carer-related support session, on meeting Carly for the first time and realising that she was also caring for somebody with PD she had recommended and provided the contact for the dance group.

Accessibility and Locality

The groups listed in Table 16 were in London and the Home Counties. To access those based in London carers often used public transport, however outside of London the car was the main means of transport. One carer (Margaret) and her husband, regularly travelled by bus to access a Parkinson's dance group some distance away. Some of the carers were in their seventies and eighties and continued to drive while others managed different bus, rail, and train routes to get to the various locations. It was evident that changes in the care-recipient's or carer's abilities to manage this travel would negatively impact on their involvement with this aspect of their network.

6.4 A Lifeline: The Network in Action: Accessing and Utilising Resources

This aspect will now consider the outcomes of the carers' involvement with the TSOs. Caring can have both positive and a negative impact on the carer's quality of life. Caregiving burden and its effects on the physical and mental health of those caring for somebody with PD have been described in the introduction and literature review chapters (Martínez-Martín et al., 2007; Schrag et al., 2006; Williamson et al., 2008). The reasons for joining the groups initially often centred on information seeking. However, as the carers involvement increased the data revealed many other benefits and outcomes that such group membership could provide. Membership and involvement with the Parkinson's UK or PD related groups was predominantly by both individuals in the care dyad. However, it must be recognised that several carers and care recipients were involved in other TSOs. Some were carer-focussed and offered support and activities directed to the carer. Others were focussed on the care-recipient but by virtue of the care recipient's involvement there were vicarious benefits for the carer.

Several participants used the term *lifeline* when discussing the benefits of membership. Early in the interview with Caroline, when the Parkinson's groups were mentioned, she stated:

Caroline: *It is...it's like a...a lifeline really you know they're...they're there...and even when there's not meetings you, you can get in contact by phone. ...You can't ask for anything more than that can you...?*

Carly lamented the closure of a local carer centre due to austerity and the local borough cutbacks. She commented; *[it] is so sad because for so many people it's a lifeline*. The centre had organised a wide-range of carer-focussed activities and had been prominent in the local community. For her it had been an entry point to access local support and advice and had led on to a range of opportunities. Carly was clear that the loss of this service had resulted in many carers losing much needed support and assistance. Thus, as the data was analysed this concept of a *lifeline* and how involvement with these organisations offered a means of escape from a difficult situation became a means of understanding the data. The data uncovered a range of positive impacts on the carers from their engagement and participation in these groups. This was particularly in relation to the following areas:

- Carer Wellbeing
and
- Support with Illness Work

For many their entry in to the various Voluntary and Community Organisations (VCO's), whether initially through an online forum or directly by attendance at a local group had been with the aim of discovering more about the disease and finding strategies that might aid in dealing with the illness. However, as time progressed and for some, other opportunities became available or were sought in terms of VCO involvement, further benefits and outcomes developed particularly in relation to the well-being of both the carer and care-recipient. These overarching themes will now be examined in more detail.

6.4.1 Carer Well-Being: Cognitive and Physical Well-being Activities, Outings and Holidays

Activities, outings, and holidays were a hallmark of the Parkinson's UK/ PD associated groups. There was a number and range of events that were organised on a regular basis. Across the 20 participants many were discussed at interview or named during

the period they completed the diary. These added to the enjoyment of group membership and offered further opportunities for respite and restoration from the illness. As carer engagement with the group(s) increased their involvement in a range of activities and events became more extensive. Many activities were focussed on cognitive and physical functioning and were primarily directed at supporting and improving the physical and cognitive health of the care-recipient diagnosed with PD. However, these activities were also very beneficial to the carer in several different respects. For Carly (as was described in chapter five), all aspects of her and her husband's involvement with Parkinson's UK and associated PD groups were also completely intrinsic to their personal community. Their entry to the dance group had opened a very particular and, in her words, *special* opportunity that had proven beneficial not only to her husband Robert (who had been a professional musician) but also to herself as a carer. Thus, these activities offered mutuality in sharing a positive experience together. Here is an extract describing the dance group for both Carly and her husband.

Carly: Oh it's brilliantit's in terms you know like school terms sort of thing and it's based on a different dance every term, so you're doing different moves...umm you know it's, it's really wonderful, it's really wonderful...

JS: ... tell me something about what you get from that...

Carly: First of all with the dance classes you're getting...umm sort of wonderful tuition with exercises all based on dance moves and based on a particular dance, like [X], whatever, so umm there's a lot of stretching exercises and dance moves incorporated into that, so we are all learning routines so this is using, using you're cognitive functions as well, its using umm, umm arms, legs whatever...

JS: Range of motions...

Carly: range of motions yes that's right, that's right...you're interacting with the teachers who are just wonderful, umm and as well as being...having a serious side to it, of, of moving those rigid...limbs and muscles, everything's tightened up in PD...

JS: Yeah, yeah

Carly: *As well as the beneficial effects of that, there's the social aspect of it. All the dance teachers as well as all the people going have wonderful senses of humour so there's a lot of humour injected into it...umm there's some singing involved as well err and there are musicians playing for us, we interact with those people as well...*

JS: *Which for Robert I suppose is special?*

Carly: *Yes its lovely...its very, very good...so the whole thing, it's amazing that this works so well with so many people.*

Vicarious Enjoyment: Respite and Restoration

The fun and enjoyment in taking part in a range of activities was described by many of the carers. Interestingly, the carers appeared to gain both personal pleasure and vicarious satisfaction from their partners' enjoyment. These extracts also revealed moments and time spent together that was restorative and gave a sense of respite from the day to day living with a long-term condition such as PD.

In Elizabeth's interview, her involvement and that of her husband's in the singing group had many benefits on several different levels as captured in these extracts from the interview and diary data.

Elizabeth: *Oh I love to sing*

JS: *Tell me about the singing...*

Elizabeth *Singing is the best thing of all because when you are singing you can't think about anything else[the musician] stomps around in his boots, with the group sort of beating out a melody...and...it's his method and he believes that singings is really good for ill people and singing is good for all sorts of things...*

JS :*Does Mark enjoy it...?*

Elizabeth: *Gawd yes...he loves it...absolutely loves it...*

JS: *So you go together...?*

Elizabeth *We always go together umm...and I haven't thought about bloody Parkinson's ...*

JS: *Even though you might be with a group with Parkinson's*

Elizabeth *It doesn't matter...you're not thinking*

Elizabeth mentioned the Parkinson's singing group twice in the 20 days she maintained the diary, and as in the interview, the fun and distraction from the illness this offered was a real benefit.

Elizabeth: Highlight of the week! Singing with this group really cheers us both up. No time to dwell on our misfortunes, the singing is totally absorbing
[Elizabeth: Diary Extract]

Only four carers had formal substantial social services support, one carer had weekly respite from the organisation Crossroads and one carer had regular paid support from her brother. This input was the only directly guaranteed care and respite. Some of the carers in the study maximised ad-hoc respite opportunities provided by the care recipients' involvement with TSO activities. In this study those activities utilised for this purpose are highlighted in Table 16 with an Asterix. During these often-short periods of time, carers pursued their own interests or caught up on household chores.

In this context, some also described role overload and role captivity with a need for time away from the care recipient and the caring role (Zarit et al., 1986). The sense of being trapped and overwhelmed was highlighted in the data. In her diary, Elizabeth commented on a fellow carer being able to go abroad without her husband, however this was not possible for her.

Elizabeth: Because of Mark's age, time away from home is impossible for me. It's like being under house arrest.
[Elizabeth: Diary Extract]

Maureen was being treated for depression and her husband's deterioration over the previous six months had altered her perception of the caring role. In the diary she had highlighted meeting for coffee in town with the wives she had met through Parkinson's UK. This she did while her husband attended a Parkinson's UK activities group. She had specifically encouraged her husband to attend that meeting so that she might have some time for herself. This extract formed part of the discussion on her need for time away from the role with her sense of being *on duty* described.

Maureen: *Yes, that's where it must have come, it must have come to me that I'm on duty from the minute I get up until the minute I go to bed, and it's all the time umm oh have you taken your tablet...? You know, have you been to the loo...? Coz that was one of the problems on holiday as well umm the loo, it was never in the right place of course, too late umm so yeah I think you're not off duty, you know I sit, perhaps sit and read umm but then I think, I haven't heard him for a while you know where is he, is he alright...?*

JS: *I mean it was interesting that first time I met you, one of the things you said to me was, I was looking forward to going to bed...*

Maureen: *That's right, you suddenly realise that, I thought why am I like this, you know, it might be 9 o'clock and I thought oh good, it'll soon be bedtime umm yeah that's weird but I think that's what it is, I then feel off duty...*

Tom was grateful that he was in receipt of respite support from the organisation Crossroads. However, it was only for three hours per week and his need to have enough time be able to carry out an activity or visit without feeling time pressured were highlighted in the following extract.

Tom: *Crossroads comes for three hours.....by the time...umm I leave I've got two and a half hours or two...*

JS: *Because you've got to be back on time...*

Tom: *I've got to be back, so I'm, if I go to my sisters, I mean I cycle over to her [name of place] once or twice, a few times, but you know by the time you get there and have coffee, you sort of, oh god I've got to go in a minute so you don't relax...*

At one point, he'd been given an extra, longer session and here he describes being able to travel and meet his son in London where he works.

Tom: *Just walking and, and, and just, we, we went to a little museum up there, just where [name of place] is and err, it was just lovely, I've just never done that before, I've always wanted to do it, so I said to the lady who sat and she arranged it...and err so I did get my extra hours but that's the only time...*

For this carer there was an increasing need for a greater physical and mental separation from the care-recipient and the illness, that wasn't being accommodated through TSOs or the statutory sector.

Gary had taken up bowls with the local carers group on the days that his wife attended a day centre. It was clear that he was getting pleasure and relaxation from the opportunity to learn this new skill away from his caring role.

Gary: But with the bowling it set's your mind, because you have to concentrate ...so it takes your mind off things (laughs)...

JS: Ok so that's another aspect of it in a way, getting out and then something taking your mind of things...

Gary: Otherwise I probably, while Paula's at the day centre, I go for a walk or go around the shops but really just...I say wasting time, it's not wasting time but it's not productive in any way...This is more productive...

Self-Esteem

The carer's involvement in the groups allowed the utilisation of existing skills. Four of the participants (Adam, Debbie, Tom and Denis) used the opportunity to utilise skills that they had previously acquired in their working lives, and this appeared important to them. This engagement gave the carer a sense of mutuality in their relationship with the group and added to their self-esteem. Adam had been keen to offer his engineering and technical skills in support of the group's activities.

JS: And you...you've obviously got quite involved yourself haven't you...?

Adam: Oh yes...yes well...umm...(laughs)...umm...[Julie] is running the group...OK umm...people have problems with their voice with Parkinson's ...we could do with amplification...because of my past engineering experience umm...she [Julie] needed some technical support...so we got umm...amplification equipment...so I did that and also discovered that when you are meeting in the big room a bit of background music is actually quite helpful in setting the atmosphere...we needed a projector...and...there was lots of things...so that was the support group ...I go to moving with music, coz there's three of us, do the teas.....[The overall branch] have a monthly meeting and we started going to that. But it wasn't long before they asked Julie

to stand on the committee ...and...they were in need of some sort of technical support, so I started helping them, providing amplification...so I got to know the people there and they got to know me...

JS: Well.....what, ...in terms of your caring role...what do you feel you get being part of that... ..?

Adam: ...what do I get out of it...umm...well I'm able to help other people...and that's a good thing...

For Denis applying his acquired management skills had been important in his role as Chair of the local Parkinson's UK branch.

Denis: Well, I tend to...by nature and by my work over many years tend to be a bit of a manager one way or another, always looking at how things are organised and what else we can do and organise and other people to do it, you know, that's my nature, what I enjoy doing actually, its creative really if you do it properly...

JS: So you felt you wanted to use those skills that you had in terms of managing that group...?

Denis: I did, there's no question that I did...err...started various things that they weren't doing, you knowI mean while I was in those three years, increased the membership quite a lot,.. I produced a branch leaflet, took about 6 months to do... Because err...there's quite a bit of information in it and I got the colours right so it sticks on the wall in a Doctors' Surgery, they see it.....and I'd not done that before at all, it was totally new to me, so it took me a long time, I bought a programme to do it and I had to learn to use that.....it's satisfying when you've finished, and then I got a list of all the surgeries in the area [name of three towns] , doctors surgeries, chemists and things like that...and err...I located 16 surgeries, where those leaflets all went into...So it's those sort of things that I tend to try and get involved in, trying to push something forward...

Debbie was very busy in her local group organising a range of activities, including holidays and trips as well as producing a newsletter. She too had wanted to use the

skills that she had developed in her working life in her role as treasurer and social secretary of her Parkinson's group.

Debbie: I think I could see a bit of, see the whole thing from a whole per, perspective because I've worked with a charity as an administrator ... so I've got a lot of experience of committees and arranging events and this sort of thing, and I thought I'd be quite a good person to see the overview.

Thus, for each of these individual's personal satisfaction, pride and mutuality was gained in working with and for the group.

Social Companionship: *Wonderful support groups...wonderful friendships.... so much happiness...*

The friendships developed through the groups were particularly important to the carers. Many had developed deep friendships and had regular contact (some face to face, some by telephone or email contact) with members outside the usual meeting times. Debbie as already described was very active in her Parkinson's UK group and called it *our own support group*.

Debbie: Doreen rang me today to see how things were and I ring her....

[Debbie: Diary Extract]

Adam discussed the friendships he had formed with two other male carers at the group. Together they talked and discussed their role while supporting and helping the running of their branch. While keeping the diary Adam also made this comment about his attendance at a Parkinson's UK meeting.

Adam: Don, Bob and I spend an hour together while we prepare refreshments for the Parkinsons' .. group (x21). This is the only contact Don has where he can share his concerns ... he needs a break. Mutual support.

[Adam: Diary Extract]

As previously described, in chapter five Carly had developed an extensive network of friends through her involvement with Parkinson's UK and a local carers group. Towards the end of the interview, we explored the significance of these groups for herself and her husband.

Carly: What it does is it...it makes having this condition, living with this condition, far more bearableRobert said once...there has to be some positives in this...you know, you're lumbered with this awful condition and thank god we've found some positives in it all.....well because we've been blessed in, erm, finding these wonderful support groups which have turned into wonderful friendships, people we can't wait to spend time with because there's so much happiness...

JS: And fun?

Carly: Yes fun, lots and lots of laughs, lots, lots of touching, lots of hugs, terribly important to your overall wellbeing...anybody with any condition, even, even us with not the physical constraints and problems of a, a severe disability like Robert has, we need affection and love and touching and lots of laughs because otherwise your life is just full of stresses and strains or just...yeah fairly bland, but err, the side effect of Ray having PD is a whole new world's opened up to us...

6.4.2 Support with Illness Work

Involvement with the TSO's, particularly Parkinson's UK and some of the other carer groups appeared to offer opportunities to engage in expanding not only the carer's knowledge and understanding of the disease but through peer support and informal professional contact, developing strategies and resources that could aid the carer in their role.

Go to People, Network Bridges, Opening Doors

The resources within the groups were significant. Primarily, alters i.e., other people connected to and within the groups became instrumental sources of help and support for many of the participants, and for many reasons. During the interviews the same key individuals would be named by different participants. Some of those named were employed by the organisation others were members. In terms of those named

members, some had PD themselves whereas others were carers. Each of these individuals became 'go to' people and they were viewed as being particularly dynamic and useful for their knowledge and skills. Parkinson's UK utilised and employed Information and Support Workers (ISWs). These were assigned to several local groups across a geographical locality. These individuals were strategically placed in the Parkinson's UK network and their role was to help co-ordinate activities, offer advice, support and signposting to further resources or opportunities. In other carer groups and TSOs listed by the participants, key individuals or roles were also identified that acted in a similar way. One ISW was singled out by several carers for his instrumental help, advice, and support. This included advice on financial matters including benefits and council tax and support accessing specialist equipment. The ISWs and another named individual (Joan who had PD) all occupied a particular place in the network with connections to two or more Parkinson's UK or PD associated groups. As described by Granovetter (1973), these ties acted as 'bridges' between the groups that formed more denser networks and they facilitated the transmission and diffusion of information across the different groups in the network.

Health Professional Contact

From the interview and diary data it was possible to ascertain that the carers through their TSO involvement had access to several health professionals separately to their usual formal contact via the hospital, GP, or community services. Health professionals were regular attendees at the local meetings (particularly for Parkinson's UK) which meant more informal contact with the following: Consultant Neurologists; Parkinson's Nurses; Pharmacists; Dieticians and Physiotherapists. These opportunities were used to gain further knowledge and information about the disease, medication, and evolving therapies. Julia and her husband Brian had used a regular 'spin off' informal meeting aligned to their regular Parkinson's UK group to discuss many different things with the Parkinson's Nurse and a Consultant Neurologist who also attended. These were their *meetings to go to... you always learn things*.

The Knowledge and Experience of the Group

Sharing knowledge and experiences within the group was an important aspect of membership as the illness progressed and the care trajectory evolved. Discussions were had on a range of issues that included practical matters associated with

managing a disability; the experience of local health services including members' opinions on the competence and expertise of the Consultants and other health professionals involved in their care; and the changing symptomology and manifestations of the illness as it progressed.

Sharing experiences through social comparisons about the nature of the condition and its symptomology with others helped the carers to further understand the disease process and make sense of the biographical impact on the care-recipient and the impact on the relationship of the carer and care-recipient.

Adam : so its...its, its useful to be able to draw information from other people who are caring and other people who are suffering...just to satisfy your own mind...that these symptoms are not something...umm...that need to be pursued other than the way we are already...

In a diary extract Adam also noted his interaction with two friends at a Parkinson's UK meeting about the effects of PD as follows:

Adam: Exchange notes on caring – helpful/encouraging:

Difficulty in PD person getting into bed.

Difficulty in finding comfortable position ... at times not possible – muscles tense – rigid – spasm.

Difficulty in moving ...

Legs and Arms feeling cold.

[Adam: Diary Extract]

Margaret and Elizabeth through social comparison noted their observations about others in the group who were having more difficulties than their husbands and this seemed to give them reassurances that things were not so bad in their own situation.

Henry also discussed his experience of the Parkinson's UK group's use of social comparison.

Henry: [At a recent Parkinson's UK social lunch] ... when was it, Wednesday this week, we were discussing sort of sleeping patterns (laughs) between us

and our partners and so on, umm so it's just amusing and...ahh confirming really that sort of things that are happening as far as Sandra and I are concerned were just sort of confirmed at the table...

And later discussing how he used the social contact as a means of support with the Parkinson's UK group.

Henry: ...you might sort of compare notes basically...umm somebody might approach you and say oh...umm...we're hoping to apply for blue badge or something like that you know and then you would offer your experience of that and the process and so forth. I might go to somebody else and say you know, umm what do you, what's the latest medication on the markets? That sort of thing...

As highlighted in Henry's account, the importance of medication in the treatment of PD meant that medicines management was a regular topic of conversation in the groups. The range, action and dosages of the medications prescribed through to the efficacy of brands, tablet availability and quality of the local pharmacists were all part of these on-going discussions.

Gary, who had expanded the range of carer groups and activities that he was now associated with, found his recent attendance at six carer training sessions very beneficial. They had been well-coordinated, the topics were interesting and the group, despite caring for individuals of all ages with many different disabilities and conditions had obviously worked well together.

Gary: Everybody kind of fitted in... everybody was sharing, and everybody was quite willing to listen to everybody else share...

Later in the interview, he also discussed the Alzheimer's group he was involved with.

Gary: The Alzheimer's meeting...that is a group of carers, just carers and we go round the room sharing, information about our own situations and sometimes other carers pipe in and say what about this or can't you do this or,

we've had this problem and done this umm...and obviously it's being run by professionals...

It was evident that involvement with these organisations facilitated the development of contacts that were useful in supporting the carer in their role. The sharing of knowledge, skills and understanding within the groups through peer support and through contacts with professionals and others with specialist knowledge (such as the ISW) enabled the carer to support and manage the work involved in dealing with a progressive long-term condition.

6.5 Summary

The voluntary nature of TSO membership meant that the carer and care-recipient had greater agency, control and choice in shaping these aspects of the network. However, entry into these groups was dependent on several factors. Extrinsic factors were important in terms of the initial entry with an on-line presence, accessibility and group attributes that facilitated a conducive ambience influencing carer and care-recipient engagement. Intrinsic factors associated with the carer and care-recipient were complex and were uniquely interwoven across each of the care dyads. Fear of the future and the stigma associated with this debilitating disease were factors that the carers and the care-recipients had to confront as they considered joining the Parkinson's UK groups. Further nuanced communication within the care dyad regarding their involvement and entry to the groups was also needed as each considered their needs and that of the other person. This aspect of the network also demonstrated a dynamism and evolution over time. Bridging social capital was evident and there was a resultant tautology of involvement in these networks. Thus, as carers began to transit across the network widening their access and participation, with increased contacts and interactions they accessed more resources which had beneficial gains for both the carer and care-recipient. For some carers as they extended their involvement across in the network, they too became bridging ties as they sign posted others to resources and opportunities.

For several, these groups became an integral part of their lives and were viewed as a *lifeline* in terms of the benefits that both the carer and care-recipient gained in terms

of their well-being and support with illness of work. This integration with the groups, as their social relationships developed, led to reciprocity and mutuality that further maintained and propagated the network. Thus, the homophily of experience (Perry & Pescosolido, 2010, 2015; Sutor & Keeton, 1997; Sutor et al., 1995) of PD, fused close relationships and the members of the group became closely bonded as they connected with each other. A transformation was therefore evident as bridging social capital evolved into that associated with bonding social capital. Notable, between the TSOs and the formal sector was a symbiosis and synergy. Information gained through involvement with organisations such as Parkinson's UK was used to increase the carer and care-recipient's knowledge in a range of ways. As will become evident in Chapter 7, this knowledge was used in negotiation with health professionals and facilitated navigation around the health and social care systems. TSO membership also gave access to health professionals outside of the usual formal setting thus providing opportunities for further discussions and exchanges about treatments and care.

Chapter 7: Results

Health and Social Care Provision: Establishing and Maintaining Links

7.1 Introduction

In this chapter, the contribution of the health and social care sectors in relation to the role and support of the carer will be explored. The emphasis now moves to address the health, medical and social care that formed the formal care delivery. The concept of linking social capital will be considered in relation to these meso-level connections between the carer, care-recipient, and the formal networks of care. In long-term conditions such as PD it is recognised that a range of health professionals and other formal services may become involved over the course of the illness. As previously discussed, (see Chapter two, section 2.4), PD is a complex neurological condition with wide-ranging cognitive and motor effects, that can lead to individuals experiencing unique symptomatology and increasing disability. The course of the disease can be protracted, and consequently there may be wide variations in the type and range of services involved. In this chapter the range of formal services that the carer encountered and interacted with in caring for their spouse or parent will be examined in terms of their network of care. Utilising the concept of linking social capital and Cantor's social care model (1979, 1991), the interface between the carer, care-recipient and those meso-level connections to other social domains and institutions encompassing health and social care provision will be examined. How these linkages are created and developed between the formal networks of support and the carer are explored to elucidate the forms, functions, and associations of this aspect of the network. The accounts presented uncover the intricate social interactions that occur at the interface between the informal carer and the formal care providers. This is examined in relation to the carers' role as a network broker or 'go between' in coordinating the network through communication, negotiation, and the division of tasks.

In examining the data related to the formal health and social care providers most directly involved with the care-recipient and dyad several themes and subthemes

became apparent. These are outlined in Table 17. Each theme and subtheme will now be discussed.

7.2 The Range and Provision of Formal Services Shaping the Network

Although each care-recipient had PD there were a wide-range of heterogenous formal services identified that were determined not only by the disease and its presenting symptomology but also based on the other conditions associated with ageing that were affecting different individuals in this cohort. Geographical location, local commissioning arrangements and the range and scope of available service provision were significant in configuring this aspect. However, accounts given by the carers also demonstrated the agency of the care-recipient, carer, or the dyad together, in shaping and determining the formal care that they would receive. This was within the context of their own situations and personal resources be it social, economic, or cultural capital. Economic resources meant that for some who were able to afford it, either regular private care was sought, or one-off arrangements were made.

In Table 18 the specific health professionals or services involved in supporting or managing the individual with PD are listed. These were established through the name generator, diary, and interview data. A total of 17 different types of health professional across all the participants were involved in care. A social worker was involved with five of the cases and four care-recipients were in receipt of social services domiciliary care. Although health and social care was predominantly provided by the NHS and the local authority, Elizabeth's husband had an extensive range of private care. One carer (Susan) was also supplementing social services domiciliary care with a privately paid arrangement with the same unqualified carer.

Table 17: Health and Social Care: Concepts, Themes and Subthemes

Over-Arching Concept	Theme	Sub-theme	Key Elements
Health and Social Care Provision: Establishing and Maintaining Links	The Range and Provision of Formal Services Shaping the Network Navigation: Forging and Developing Links:	The Health and Social Care Trajectory	Transitions and Turning Points Disparate Access Private care Choice and control
	The Network in Action: Developing and Maintaining Relationships The Network in Action: Accessing and Utilising Resources	Facilitators and Barriers to Formal Support The Role of Gatekeepers The Carer as a Network Bridge, Broker and Co-ordinator	Reciprocity and mutuality Trust, respect, and carer recognition Tension, conflict, and frustration Navigation and negotiation

Table 18: The Range of Formal Providers Involved in the Care-Recipients Care

Carer	GP	Neurologist(s)	PD Nurse	Pharmacist	OT	Physiotherapist	District Nurse	Medical Supplier	Social Worker	Day Care	Home Care	Other*
Carly	•	•	•	•								•
Cilla	•	•		•						•		••
Mary	•	•		•								
Elizabeth	••	••	•	•		•						••••
Julia	•	•	•	•								•
Harriet	•	•		•								
Margaret	•	•		•								••
Susan	•	••	•	•	•	••			•		••	
Monica	•	•		•								••
Adam	•	••	•	•	•							•
Lenny	•	•		•	•	•						
Dawit	•	•••		•		•	•	•				
Henry	•	•	•	•		•	•	•	•	•	•	
Caroline	•	•	•	•								
Debbie	•	•		•					•	•	•	•
Gerald	•	•		•	•	•						
Tom	•	•		•		•			•			
Denis	•	•		•								
Maureen	•	•	•	•	•	•						
Gary	•	•	•	•	•				•	•	•	••••

• Denotes publicly paid for services. • Denotes privately paid for services.

*Other NHS: Low Vision Clinic; Incontinence Service; Ophthalmologist; Admiral Nurse; Practice Nurse; Other Consultants including Gerontologists

*Other Private: Speech Therapist; Dental Hygienist; Dentist; Urologist; Orthopaedic surgeon. Chiropractor, Physiotherapist

7.3 The Health and Social Care Trajectory

In examining the formal care provision required for each care-recipient the evolution of the network over time was evident. Carers recounted their recent and historical experiences of formal care provision in the interviews. Further detailed 'real time' encounters were also captured in the diary data. Thus, a varied picture of formal care across the course of the care trajectory emerged. Recent accounts from early in the course of the illness such as Harriet's were valuable. These were compared to those from carers who were at a different stage in their caring trajectory and where the care-recipient had changing needs or was requiring more intensive or specialist formal care involvement.

7.3.1 Transitions and Turning Points

The transition into formal care and the events around diagnosis were discussed by several carers in terms of establishing the network. These changes that led to the development of the formal network were also marked by a change in the condition or dependency of the care-recipient with diagnosis and deterioration being key events. However, these points can also be viewed as a change in the independence of the carer as they transitioned into the caring role, or their role in managing care altered as more services were required. Thus, for some, during the care trajectory, sudden alterations in circumstances or events precipitated significant changes to the care network. Throughout the care trajectory there was evidence of the carer and care-recipient also exerting influence and control to determine the structure and function of the network. The intricate and delicate social and relational dimensions between the carer, care-recipient, and those in the formal sector, be it health or social care, also were important features. Throughout these changes the carer attempted to balance their own and care-recipients needs through liaison and negotiations with the providers. The interdependence of the carer and care-recipient were evident. It therefore required the carer to respond and adapt to the changing situation and be cognisant of the care-recipient's changing needs and dependency.

The following became sub-themes that allowed examination of the evolution of the formal structures in the care network: the transition into formal care; disparate access to formal care; private care; turning points and choice and control. Each of these will

be discussed. Excerpts from the interviews and diary data alongside vignettes will be used to examine and illustrate each theme.

7.3.2 The Transition into Formal Care

The nature of PD as a neurological condition meant that all the care-recipients had a neurologist involved in their care and this was normally directed via a local general hospital, neurological specialist centre or large Foundation Trust. The care-recipient's diagnosis of PD and transition into formal care varied across the 20 cases. For some the initial journey was straightforward with a referral from the GP to a neurologist at the local hospital. However, for others the complexity of the illness and variable symptomatology meant that referrals, treatment, and diagnosis became complicated with varied routes and trajectories. This disparate access and varied formation of the formal network will be examined.

7.3.3 Disparate Access to Formal Care

Carers and care-recipients found themselves at the interface of the informal and formal care sectors. As these extracts will demonstrate access into the formal sector was disparate. In shaping the network, the dyad also called on their own personal resources, be it social or economic capital or previous experience and knowledge of the system. At times the carer and care-recipient collaborated to manage the trajectory. At other points, as the disease progressed, the carers found themselves alone trying to negotiate and navigate complex health and social care systems.

Harriet: *I think he was avoiding it really*

For Harriet and her husband, it was early in the disease trajectory. He was now being monitored by the neurology team, did not require medication and needed very little support. Harriet felt that he was avoiding accessing care that might be beneficial, so she had encouraged him to contact a specialist multi-disciplinary neurological service via his GP (which the carer had knowledge of due to her own diagnosis of Multiple Sclerosis).

Harriet : The physiotherapist there helped me a lot...she was very, very good...and there are all sorts of service there which are very, very helpful...so Bill was err. I think he was avoiding it really...umm I said you know you really

ought to go up there...go and see the PD nurse...she...talk to her about anything that's bothering you...she knows...she understand...I said...that's her field...so anyway, he's been up there once or twice.

In this excerpt, Harriet appears to be facilitating her husband's entry into the realms of formal care through her own knowledge of the available resources and her own understanding of the disease trajectory. However, her husband's reticence and willingness to engage with other services had been evident and it was ultimately his choice to access this specialist facility. As the disease progressed or where there were crisis points, the carers recounted their need to navigate through the health and social care system. This was often alone since the deterioration in the care-recipient meant that they were unable to co-operate or contribute to seeking out care.

Susan: *Initially it was...mind boggling*

For Susan, her husband (Kevin) had deteriorated quickly and had suddenly needed a lot of professional support. However, dealing with several providers of care had added to the complexity.

JS: ...I suppose suddenly you had all these health professionals in your life which you obviously didn't have before... ..

Susan: I suppose the more you get into you know whatever your partner or husband is suffering with...the more you find out...and obviously the more you find out the more you're able to help yourself, but initially it was...mind boggling and umm...just...getting hold of the OT (occupational therapist) and getting hold of the physio because they changed offices in [X]...the girls [professional staff] gone back to [overseas]...the telephone number changes and umm...that, that was an awful few months...

JS: And because he was so ill as well...

Susan: He was so ill...I can't get hold of anybody and he'd get on the phone and get all confused and...I thought oh gosh, what are we getting into...but the more you become accustomed to the fact that your husband isn't going to get any better, the more support you can build around yourself the better you are...

Through a GP friend Susan had heard about a specialist PD service based outside their area. Susan had managed to get her husband referred to the service by their own GP sometime after the initial diagnosis. However, the services that Kevin was under crossed two commissioning groups and that now was now causing problems.

Susan: Well...I think if we'd gone initially to [specialist PD service]...we wouldn't have had those months of trouble...umm...but you see the other thing about [this service] ...its [different authority]... And anything to do with occupational therapy...such as...the bed...the handrail...walking frame...stick...hand bath, handles and seats...they umm...[specialist service] can say yes this is what you need but sorry we're not in your area.

At one-point Dawit and his wife had explored specialist PD services in the EU, since they felt they needed greater expertise to manage the disease. Their contacts overseas alerted them to a service and had facilitated an initial visit. However, after some discussion with the GP they had finally been put in contact with the same specialist PD service as Susan and for them this too was outside their local commissioning service. They too had experienced the complications across the commissioning boundaries with OT and other enablement support which had led them to remain with their original hospital provider.

Thus, in each case different forms of negotiation were evident as the carer interacted with the care-recipient, health and/or social care services. The carers' intricate understanding of the capacity of the care-recipient to manage and deal with the situation was apparent. At the same time personal resources (friends in Dawit's case, a GP contact in Susan's case or the carer's own experiences in Harriet's case) also played a role in harnessing and accessing services that were perceived as potentially beneficial to the care-recipient.

7.3.4 A Turning Point: The Entry of Social Care into the Care Network

Only four of the care-recipients were receiving formal home-based social care to support them with washing and dressing usually in the morning and for one care-recipient in the evening also. Two of these care-recipients also attended day centres organised by social care. To receive this support a social worker had undertaken a formal assessment on the needs of the care-recipient. In the following vignette the

introduction of formal paid social care into the life and homes of the carer and care recipient is explored from the interview account.

Debbie: *They're going to have to carry on.. ..I can't do it...*

At the first meeting when the network data was ascertained it was evident that her husband's cognition was deteriorating and an Admiral Nurse (because of her husband's dementia) had met with the carer to consider greater involvement of formal care services and respite for Debbie. However, as the network was discussed, Debbie expressed a reluctance about having more support, partly based on her own concerns around the disruption to their daily and weekly routines and her husband's likely resistance to the involvement of other formal agencies. In the interim, between completing the social network data and undertaking the main interview, Debbie's husband had suddenly become ill and was hospitalised for four weeks. Prior to hospitalisation, the only respite that was available was one day per week when her husband, Matt, had attended a local, charity funded, day centre that had been organised independently by the couple i.e., not through social services. The main interview for this study took place after his return home from hospital and, at the time, a six-week enablement package was about to finish. Therefore, the changes in their home circumstances had been sudden and abrupt as domiciliary care became part of their lives. Formal paid carers were providing care twice each day, seven days per week and these new arrangements were discussed at the interview.

JS: Are they going to, are they going to carry on or will they stop quite soon then...?

Debbie: Umm on the 8th we're going to be assessed and they're going to have to carry on, I mean we're going to probably have to pay, I don't know how it all works from now on...

JS: do you want them to carry on...?

Debbie: Oh They're going to have to carry on.. I can't do it...

Debbie discussed her increasing concerns about Matt's physical and cognitive decline before his recent illness and realisation that more care may be needed. These following excerpts illustrate the dilemma that the carer had faced originally broaching

the idea of homecare with her husband who had been strongly against it, and again now that care had begun in the home.

Debbie: : You see...I knew because he wasn't shaving very well, some mornings I thought he hadn't washed.....and there's various things that I could see that he wasn't doing and this is the only thing that he does and he wasn't doing it...: And I'd said to him, Matt we're going to have to get carers in, and he said, if you get carers in I shall leave home...it's very hard, so umm of course in hospital for four weeks he had everybody caring for him didn't he, so it was very good to carry it on....

JS: Do you imagine that if you're assessed that it could be for 7 days a week, twice a day would that be the plan, 7 days...?

Debbie: Yes umm...yes definitely...if we can afford it, I hope. We haven't got much money, so we might be able to umm...but umm its useful now, its, so long as Matt sort of...feels happy about it, I'd like him to feel happy about it, but because he doesn't speak much its quite difficult to work out, coz he looked really daggers just now [during the interview a paid carer had arrived for the evening session], umm and he's a very nice man this one that, that's come today umm...

This account demonstrates that the abrupt changes brought about by the recent illness had introduced formal care within the home and offered a rational and justification for its continuation. This scenario highlights the fine balance of dependency and need between the carer and care-recipient. Debbie and her husband's need for support, her husband's misgivings, whilst Debbie is hoping he can accept the change. Concerns about the on-going affordability and availability of this care were also concerns for the carer and how that might impact moving forward.

7.3.5 The Role of Private Provision in the Formal Care Network

Most of the formal care identified in this study was provided by the NHS and through Local Authority arrangements. However, there was discussion with four of the carers about privately arranged care. Two of the male carers discussed accessing a private neurologist. For Adam and his wife, a three month wait for a consultant neurologist meant that they accessed a 'one-off' private appointment to confirm the PD diagnosis

and begin treatment. Although they had returned to the NHS after this. For Denis and his wife Paula they had decided to access a private consultant neurologist from the beginning. Like Adam and his wife, Julie, they had wanted to ascertain the diagnosis quickly and subsequently wanted regular and easy access to the same consultant. Although they had tended to visit six-monthly (which was comparable to several in the study who were accessing NHS consultant care), Denis was now reassured that as Paula's condition was beginning to change, they had a bespoke service that could enable regular monitoring and review.

Denis: And err it's a little bit the same [as the NHS] ...but at least it is a question of Paula go as often as you like and there are spells when it might be every 6 months, she will go...

JS: And how often would you see him now Denis ?

Denis: Umm it was a shorter period on this particular occasions because she's already got an appointment to see him,and it wouldn't be so long ago perhaps three, four months she saw him, but she is suffering...Because it's obviously a question of stage you're getting to...and usually I mean...fairly frequently the medication would be...changed, slightly increased,. So it's getting to a point now when we go back, I want to know whether there's anything she can have that's other than what she's doing because it's not working as it was...

JS: Right ok.

Denis: And it, it's notable but it's a very difficult situation so I said look, we go back, and we keep going back...: You can't do that with National Health Service, you won't get back, you just won't get back...

Elizabeth: *My theory is that I get all the help that I could buy in*

For Elizabeth and her husband Mark, their personal finances allowed them to readily access private care. Elizabeth's brother was also providing care to the care-recipient in a privately paid arrangement (see Chapter 5, section 5.3.8). For some years, accessing the private sector for their healthcare was the preferred arrangement for the couple and private formal care provision was certainly extensive in relation to Mark's PD diagnosis. Figure 8 illustrates those healthcare providers listed in the name-generator questions, during the diary that was kept over 20 days and at interview.

Initially in the name generator questions seven professionals were named (all but one, the NHS GP, were private providers). Mark's health was deteriorating, and, in the diary, a further four private professionals/services were named as part of his on-going care during that period. Also, between completing the diary and having the interview, Mark had been admitted to a private hospital for assessment by three different private consultants. In Elizabeth's case the involvement of the private sector was key on several levels. This private formal support was viewed by the carer as coordinated, convenient, accessible, and high-quality care. The daily support from her brother was also avoiding residential or nursing home care.

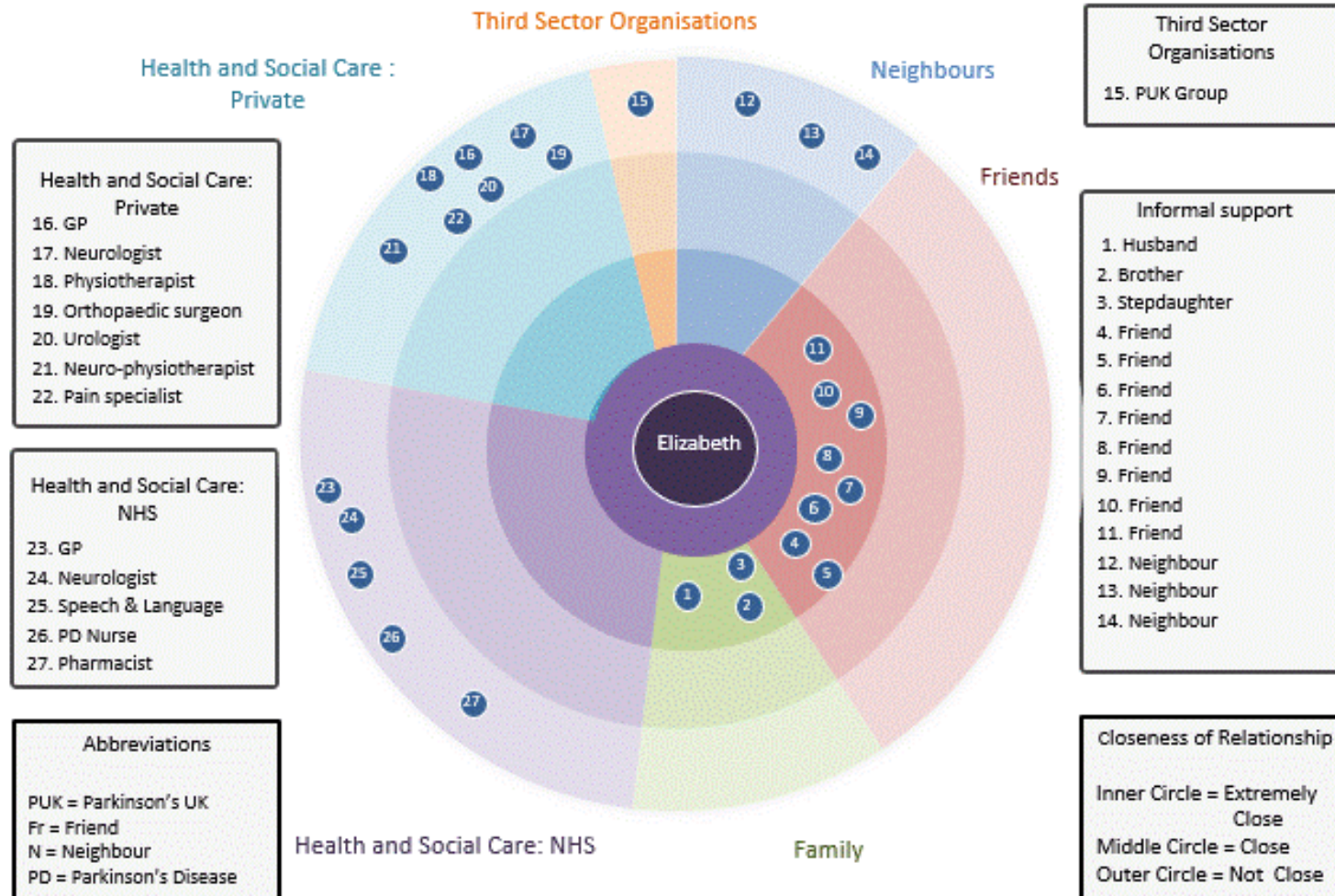
Elizabeth: ... but as Mark got progressively worse...and we needed a bit more co-ordination and that's what you know this time in the [private hospital] has been about...umm I thought no we're going to have to pay for this privately because you know they talk to each other...at the weekends and our private GP will come on Saturday...my theory is that I get all the help that I could buy in ...I absolutely don't want him to go into a home...umm and if it means that we have to have 24-hour care...I would spend it...

However, in discussing the carer's current situation her fears for the future and wondering if she could manage in a crisis, particularly when alone was certainly another reason for them to have instant access to private care.

Elizabeth: ...you're just frightened that you're not going to be able to cope...that's what I'm frightened of...

These concerns had been heightened in the last six months since her husband had required urgent attention at the local Emergency Department on four separate occasions and these admissions had been traumatic for them both. There was a sense of helplessness and loss of control for the carer during these crises.

Figure 8: Private Care: Extending the Network of Support-Elizabeth



Elizabeth was adamant that she wanted the best standard of care possible, and this was not, she believed, in the NHS. Thus, the access to the private sector offered an extra reliable armoury of support which met the care-recipient's and her needs. Thus, allaying some of the carer's own fears and worries about managing her husband's deteriorating condition.

JS: Ok so for each of those did you go to A&E...you went to your local NHS hospital...?

Elizabeth: Yes because you know you panic and don't know what to do...but I did go and see the private GP the other day, who said...you can ring...because he lives in [X] and is prepared to come...but going to A&E overnight is the most miserable experience..... we waited for 2 hours...the best part of 2 hours in the general waiting room with people being sick all over the floor...I think it was a Friday or Saturday night...and then the last thing they did was request a urine sample and he just couldn't produce one so eventually they discovered what it was...and well we were exhausted...and it was enraging because I think it was that time...umm the staff nurse couldn't find the drugs chart so she didn't give him the 6 o'clock medication so by the time I got him home the man could barely walk...

7.3.6 Choice and Control

For those who used private care, the sense of choice, control, immediacy of access and quality of care that this afforded was central to the services they paid for. In the previous accounts of the care-recipient's entry into the formal care sector there was also evidence that the balance of independence and dependency between the carer and the care-recipient affected the decisions that were taken in relation to the form and function of the formal care sector as it developed and evolved. Thus, their interdependency with the care-recipient required acknowledgement by the carer of the competing demands of their own and the care-recipients' needs. Negotiation and discussion within the dyad, on how care might proceed was evident in cases such as Harriet's where the care-recipient retained their independence and wanted to decide about accessing further care. However, where there was a deterioration in the care-recipient's condition with a resultant change in their autonomy then the choice and control regarding the decisions about care altered. For Susan and Debbie, the sudden

changes in their husbands' condition had meant that the choices made about care became predominantly their responsibility to control and direct, within the constraints of the system. In these cases, the carers attempted to balance, their-own and the care-recipients' needs whilst negotiating and organising external care and agencies. This appeared a delicate and worrying process. However, there was also a concomitant loss of control through a shifting power dynamic between themselves and the formal sector as their caring role altered and they relinquished aspects of care to others. Carers questioned their decisions and those of the formal sector as changes ensued in the care scenario.

Susan: *I thought what is this woman doing washing my husband ?*

In her interview, Susan focussed on her initial reaction to the paid carer taking on the intimate care of her husband and how difficult that had been.

Susan ...do you know she [Precious, the formal carer] started on a Friday...it would be beginning of January...she came on a Friday which is my working day...and...do you know I cried so much...I thought. what is this woman doing washing my husband...and coz then he was quite unable to do anything really...

JS: He wasn't well...

Susan : He was in a bad way...And then I got to work and the girls said to me...you know what it's gonna help you, so...:And I thought how can he be naked in front of this woman?...And he was fine, he didn't bat an eyelid...

In this excerpt it was evident that Susan had been struggling with the changes and the biographical disruption that was occurring in her and her husband's lives, and its impact on them.

Debbie: *You know there's some things that I'll do and some things I won't do...*

For Debbie, as described in 7.3.4, there was an acceptance that domiciliary support was needed. However, as their home became the space where formal care took place with the interface of the informal and formal domains of care became a constant reality. For this carer, establishing her authority in directing and determining how care would be provided in their home was integral to determining the basis of the new care

regimen. The introduction of domiciliary care into Matt and Debbie's home was not straight forward. In the four weeks from the start of the enablement package, 17 domiciliary care workers had been to care for Debbie's husband. Although aspects of her caring role had changed, particularly in relation to meeting Matt's hygiene needs, there was still much to do during this early period of home care. For Debbie establishing a workable routine with the carers that met her standards of care was very important. Liaising with the OT and physiotherapists to reconfigure their home also became a further area that Debbie was determined to have her input. It was apparent that Debbie wanted their weekly routine comprising of Parkinson's UK activities and Matt's attendance at the day centre to continue with minimal disruption. Within the initial four-week period of the enablement package, she had negotiated alterations to the timings of the visits to accommodate this daily schedule, and to ensure that they supported Matt with a bedtime routine. The additional equipment and alterations suggested to their home had proved a source of amusement and pique to Debbie. On discussing the potential changes Debbie commented about the physiotherapist assessing the home environment as follows:

Debbie: I disagreed with a couple of things...I think in a way she got the wrong end of the stick because...I tried to say to her, but she didn't want to listen.

And later in the interview after discussing further alterations:

Debbie: People sort of suggesting things that aren't practical or aren't what we're going to do is, that's the bit that amuses me in a way...umm..... you know there's some things that I'll do and some things I won't do...

Henry: *But by choice I don't think she'd do it*

In Henry's case the entry of domiciliary and day centre care had evolved over time and was negotiated between the carer and his wife. Although, on his wife's part Henry recognised that this was a reluctant decision. There was a possibility of more day centre sessions, however Henry recognised that to some extent his wife tolerated the arrangement so at the time of the interview, would not consider increasing this.

Henry: [Sandra goes] ...*just one day a week, she has her lunch there, ahh they have various activities, they have an exercise class, they have quizzes...ahh they have bingo. Sandra hates bingo (laughs) umm...and again...it gives me a chance to...have some respite and so forth and it gives a different environment for Sandra to meet people, I think...umm...again I think Sandra was slightly reluctant to go umm...in the first place, because...umm again seeing sort of...people...with in old age really, she's 67. So, she has to mix with people who are mainly in their sort of 70's, 80's 90's, umm...rather than her own sort of peer group...I don't know whether...while she doesn't find it difficult but umm...it's not by choice, probably umm... I think if you asked her and she was honest about it she would say...she'll put up with it, yes she's made some friends there and so forth and err...goes on a regular basis but umm by choice I don't think she'd do it...*

Thus, in this case a recognition of each other's needs was evident with compromise as they sought to manage the situation and negotiate the care arrangements so that where possible each could have their needs met.

7.4 The Network in Action: Developing and Maintaining Relationships

In examining the formal network, the relational dimensions within this aspect of the network became apparent and were evident on two levels. Firstly, the relationship between the various individuals be that qualified professionals or unqualified carers was instrumental and the relationship between the carer and the health and social care institutions with which they interacted was also an important dimension. At times greater negotiation, liaison and co-ordination was required to garner support from the network in terms of the carers' role. It became evident that there were several dynamic inter-personal factors that acted as facilitators or barriers to support for the carer.

These were as follows:

- Facilitators of Formal Support, incorporating; reciprocity and mutuality; trust, respect, and recognition
- Barriers to Formal Support, incorporating; tension, conflict, and frustration

Both the facilitators and barriers to formal support will now be explored.

7.4.1 Facilitators of Formal Support: Reciprocity and Mutuality

Where the carer, care-recipient and health and social care professional/worker collaborated well, there was a sense of reciprocation in providing and receiving care and a mutuality of effort. In these instances, relationships also became more personal. Susan who was caring for her husband (Kevin) too also had reached a crisis point with her husband's illness that precipitated the involvement of social services. With the aid of a supportive GP who quickly recognised Susan's desperation, they received paid carer support within two weeks. Initially, as described in section 7.3.6, this had been a difficult and traumatic time. However, Susan and her husband had gone on to develop a close relationship with Precious who had been their regular carer from the beginning.

Susan: She is...she's like a friend...in fact recently she's called me her Mum...so...coz her Mum's in [name of country]and she's patient, she's kind, she's caring, she's jovial...she's...she's everything you could want in a carer...

Arrangements were in place with social services that Precious would be the main formal carer on four days per week. However, at the weekends and on the other day in the week, Susan had struggled with her husband's care. She had therefore made a privately paid arrangement with Precious, to also work with them on the other three days. Susan was conscious that this arrangement would not be financially possible for many carers. As we discussed how Precious, and Susan worked collaboratively with her husband it was evident that caring had become a joint effort with reciprocity and mutuality. This flexibility ensured that the care arrangements worked for them all.

Carly had developed a role as an advocate for carers and their issues and had spoken at council meetings and to health professionals in their local teaching hospital. She and her husband had a good relationship with their GP and had regularly asked the couple to be part of the education of trainee GPs in his practice. She viewed this as important and mutually beneficial.

Carly: We spend two hours talking to these people and they examine Robert, umm and its...it's also very beneficial for us, it's only in the next street and that's great for Robert again, just meeting other people, meeting young people, who are intelligent people, you know, studying to be Doctors of the future and understanding that this is a very important part of their course, that our GP is introducing them to

7.4.2 Facilitators of Formal Support: Trust, Respect and Recognition

The formation of successful links with professionals and other health and social care workers was predicated on the carer/care-recipient developing trust and respect for those involved in the formal network. Furthermore, carer and care-recipient recognition and validation were also important elements of these relationships. Carly's discussion about the couple's GP also highlighted these attributes in their relationship. Carly focussed on the attentive and personalised nature of the care they received. He had rung the couple up previously to check on them and he often sent notes via Royal Mail to update them on test results.

Carly:he [the GP] has the patient's interest at heart, so you will always get very concerned care from him, he will treat you as an individual...

The role of the pharmacist was also critical in the management of the condition. Many of the carers spoke of their involvement with the local pharmacist since they would often be supporting the care-recipient in not only the collection of the drugs but also the required surveillance and monitoring associated with therapy. Gerald had been particularly impressed with his local pharmacist. His wife was having several side-effects after a recent change in her medication by the neurologist. Gerald and Lydia were unhappy with the neurologist at the time. However, as they were dealing with the

changes and the side-effects Gerald had an unexpected consultation with the local pharmacist.

Gerald: [The Pharmacist]...*he said I'd like to talk to you err on, on the, on your pills he said umm can you pop into the consulting room ...and then he explained that...one of the tablets that she takes of a night time umm is err...will react with other ones she takes at night time so either one of them umm and he...he advised you know which one and that umm...*

JS: *OK and that's when you made the adjustment then?*

Gerald: *That's right and umm...so yes we, we...yeah, we we've altered things like that you know so...it's good and he's asked, since then you know how's, how is it, OK?. It's a lovely relationship you know with them you know and umm...umm...like on occasions I'll be waiting in the queue with others who are waiting for their pills you know and if he's in there and he happens to notice I'm in the queue, he'll go...[Gerald waves]*

In these scenarios and in others recounted by the carers, developing respect and trust in the relationship with formal care providers was an essential pre-requisite to enabling the carer to fully undertake the various aspects of their role.

7.4.3 Barriers to Formal Support: Tension, Conflict and Frustration

The breakdown in the relationship with a health professional and particularly with a consultant involved in care, was recounted by several carers. In these instances, trust and respect appeared to be lost. There was a sense that the professionals were not listening to the carer (and/or the care-recipient). In the carers' accounts this appeared to be particularly related to disagreements about medication, when the regime was not effective or causing troubling side-effects. Cilla had been unhappy with her husband's treatment and with both the original neurologist and their GP. Charlie's cognitive abilities were declining, and she acted as his advocate at all the appointments for her husband. Over a period, she had felt that they were not listening to her opinion about the deterioration in Charlie. After a confrontation with each she had changed both Charlie's neurologist and the couple's GP.

Cilla: [Original neurologist]... *he said well what are you here for? Looked at the papers. Well he said, said if you can't manage him, he'll just have to go into a home right in front of Charlie and that's when it clicked. I thought no I'm not having you anymore. I used to be in touch with the Parkinson's nurse, she was backing up what he was saying. I turned round and I said...I said umm...I'm going to take Charlie off a lot of the medication...[the neurologist said] you can't do it...I said you just watch me...I said your killing my husband...and I did...I used to decrease it...I did it myself...bit by bit and I kept a note of it...*

For Adam, his wife Julie was diagnosed in her 50s. Her changing health status had come as a shock to the couple and Julie as a qualified scientist began to thoroughly research the treatment of Parkinson's Disease. Adam respected his wife's scientific understanding of her health and her knowledge about the treatments that were available. They saw a consultant privately and then continued to see her on the NHS. The consultant tried a variety of medication which made Julie much worse and led to a range of symptoms (which Julie had knowledge of), commonly seen in those with younger-onset PD. Julie was hesitant about some of the treatments prescribed and following her own research requested another medication. This was refused by the consultant.

Adam: *so...having paid for the consultation we then saw her on the NHS...and umm...we were then regularly seeing this consultant...now she's probably fine...but our...level of confidence in her...wasn't what we would have liked.*

Later in the interview:

Adam: [Julie] *asked the consultant...if she could try a particular kind of medication...the consultant said...she can't try that until she's tried something else...that it doesn't work. But Julie knew that the something else was dangerous...and she didn't want it...so she couldn't have what she wanted because the consultant refused...umm...which may have been...err...an NHS directive...so with all those complications, there was a lack of confidence...there was a feeling that the consultant wasn't really sympathetic with Julie's concerns and worries, about the whole situation...*

This unhappiness and lack of trust and confidence led the couple to seek further support. Finally, through recommendations within the Parkinson's UK group, they found a new consultant who was based locally and was closely involved in their branch of Parkinson's UK.

Adam: so...we asked for a change of consultant...we noticed other people [in the Parkinson's UK group]...umm...were a little bit unhappy with the treatment that they were getting...We went to see the [new consultant] and...he's friendly, sympathetic, understanding what's going on...and he said you're markedly under medicated...umm...he said...you need your life back now...you need to take three half tablets a day...I know there are some horrendous side effects down the line, we'll manage those when they come, you need your life back.

7.5 The Network in Action: Accessing and Utilising Resources: The Role of Gatekeepers

Where carers also expressed an increasing frustration with the overall systems and organisation of formal support as they progressed along the care trajectory, the role of gatekeepers (those professionals that control access to health and social care services), were key in shaping the care network and enabling opportunities for support. For some as they recounted their experiences sometimes in the context of many years of care, their frustrations had built as different elements of the system appeared to be unable or unwilling to enable access to resources or recognise or assist them in their role. There was a sense that provision was resource not needs-led. Sources of frustration were certainly linked to disparate service provision and the limited access to services particularly in relation to respite care. Gary's wife received regular day care since she was severely affected by PD, and her condition was deteriorating. Despite these factors and previously receiving several periods of respite their case had been 'signed off' by social services and required a new assessment.

Gary: Well social workers are a pain because they write you off as soon as they possibly can, they're not an ongoing service... you have to phone them up with

a new problem and then get allocated a social worker, they don't come and see us every four months or every six months. We had one in a couple of months ago, she phoned last week saying err, we're signing you off now...I tried to get respite, we'd had it, we had done it three times last year and then the council wouldn't give it to us this year, said we had to be reassessed... And this all took time, and the respite was a lot later than we wanted, time wise, date wise... Umm and eventually when they sent in a social worker to reassess, they, she turned round and said, I don't know why they sent me you know...

JS: Nothing's changed.

Gary: Yeah so the only thing they did do last year, every time you had a respite break they booked it as a one off instead off something on going...so it's fairly obvious (laughs)...They've now signed it as...ongoing

Susan had also had a similar experience and described her 'fight' when dealing with social services.

Susan: I think they call it [name of organisation] now, whether that's changed or not...so it encompasses all these...

JS: Like community services...

Susan: Yeah, but they're all separate and they've all got different phone numbers...that was very hard in the beginning, at a time when you are so low anyway, you're husbands so ill...why have I got all this fight on my hands...you know surely...couldn't it all work better together...?

When discussing on-going respite her situation was similar to Gary's and although in a different area the issues about re-assessment appeared to be the same.

Susan: With umm...obviously...umm...with [name of Borough] ...you were only allowed up to 6...visits of whoever...physio or...you know once you've had your six, you're signed off. It's the same with the social worker umm ..initially I thought it was very supportive but when I said [about respite] ...oh they came and re-assessed and I found out that last year I had been entitled to four weeks respite and no-one had told me...and so when I found out, I emailed the...the social worker who came here first...and he emailed back, says oh I'm not

Kevin's social worker anymore. I thought well thanks...you know...who's telling me...and you must ring the duty social worker...so that's what I did and umm.....I think for people who are ill and on their own, this is an impossible task. So, we found out, it was this other lady who was prepared to take him on...which she says once I've set up your respite care for this year, so I've been given another 4 weeks, she said the case will be closed...but I said...how can you close the case...

JS: When he's got a long-term condition?

Susan: It's progressing, it's not going to go away...but that's what they do...

Tom had been a carer for a long time, his wife was chair bound and in need of round the clock care. At the interview his frustrations with care that he had experienced over the years had led to a mixture of weariness, resignation, and anger. Throughout his interview he discussed his need for some longer periods of time away from the home (the current respite provision was limited to one, three-hour session per week) so that he could pursue some activity or visit friends and family at leisure. Over the month period that the data collection took place he had expressed his concern to his GP about his ability to cope. In that time, he had been seen by a carer navigator and the GP had also spoken to a carer champion. Shortly before the interview a social worker had also been in touch and had discussed a carer assessment. However, he felt that his needs were simple (he wanted an extra three-hour respite session per week) and despite the range of health and social care professionals involved nothing appeared to be happening.

Tom: I'm, I'm not, I'm not asking anything of anybody...I just don't want to be a nuisance to anybody but...just now and again (laughs) you feel it would be nice to have just a short break...

In considering his recent health and social services contact, Tom commented on an article he had read on the Health and Social Care Bill.

Tom: The Social Care Bill that's it...and then they're talking about that and saying now that the err council have got to do these things...yeah well if it's just [name of social worker] ringing up and saying, are you alright Mr...go away and

do something but don't, but don't ring me (laughs) you know it was awful, it really was.

These accounts certainly contrasted with Carly's experience of her and her husband's GP. As described in section 7.4.2 they had a very good relationship with their GP. He had sourced a Low Vision clinic when Robert had a particularly long wait for a referral to a specialist ophthalmologist. In her summary of this GP's approach, she commented as follows on the importance of this level of care.

Carly: If you get a good GP the stress level reduces immediately because you know they are going to refer you to the right people

7.6 The Network in Action: Accessing and Utilising Resources: The Carer as a Network Bridge, a Network Broker and Network Co-ordinator

As the care trajectory progressed it was evident that the carer became pivotal in co-ordinating the formal care network. This was apparent as the caring role became more intense and the number of actors and services in the formal network extended. When compared to this role within the informal network the carer was central to maintaining flows of information and ensuring cohesiveness through negotiation and co-ordination with different health and social care services.

The Timing of Medication and Availability of Drugs is my Biggest Single Worry

Elizabeth as we discussed her role made the comment above. The interviews and diary data clearly illustrated the complexity of the medicine regime that was a necessity to manage the PD symptomology. This complexity encompassed the range of medications that the care-recipient might be prescribed alongside the dosing, specific timing, route, and side-effects for each medication. As the condition progressed the management of the care-recipient's medication was often increasingly difficult, and the carer became central in the co-ordination and management of the prescribed regimen. The availability and access of some of the drugs could also be problematic. Brokering information, negotiating, and communicating to different agencies, to expedite

obtaining or changing the required drugs was a critical aspect of this. Most carers commented on their role in obtaining, the drugs. Furthermore, monitoring and surveillance of the drug action with information sharing on the effects to various professionals was also critical.

To illuminate this aspect of care and the carer's interface with a range of professionals involved with the medication, Dawit will be presented as a vignette. His wife's condition had been deteriorating over the preceding months. Currently managed by two specialist neurologists (based at different hospitals) she was receiving a continuous subcutaneous infusion of apomorphine, and the equipment associated to administer the drug required specialist medical suppliers. This treatment was also closely monitored by the district nursing team. While keeping the diary one of the neurologists had decided to discontinue one of the PD medications. However, this had led to a significant change in his wife's condition. At the interview Dawit explained the decisions that had been taken and their consequences.

Dawit: Yeah because [neurologist 1] referred...Zara to the movement disorder specialist, [neurologist 2] asking here for her opinion and considering options such as umm...the apo-morphine...and to look at, err review her medication as well.

Dawit then explained about the decision by the second neurologist to stop one of the medications

Dawit: this caused us so much problem...because this is 100 mg and she stopped it...but Zara had a very bad reaction after that...then the following week we had to go to [neurologist 1] and then she said umm...because it was stopped abruptly...

Like many carers in the study, Dawit also had a monitoring and surveillance role in terms of the action of the medication so he could share the information with others involved in care. In relation to the changes associated with this drug, Dawit commented:

Dawit: *it is very difficult to have a pattern because, I try to work out...when it happens...before medication, after medication, eating, eating, any other err thing.*

At the consultation with neurologist one, a decision was taken to re-start a 50mg dose of the tablet. However, due to a problem with the availability of this dosage accessing the drug became very complicated. Over a nine-day period the liaison, negotiation and action that was needed and undertaken by Dawit to rectify the situation was significant as the diary data demonstrated in 'real time' (see Table 19).

Highlighted in the extracts from the diary are Dawit's role as a co-ordinator, information broker and bridge, between the different professionals involved in Zara's care. These excerpts show the considerable time and effort required by the carer to ensure that this aspect of his wife's treatment could be properly managed. This aspect of support to his wife also clearly highlighted the extent to which carers contribute to medicine work for those with PD. This aligns to previous research that has clearly elucidated the work of chronic illness and the role of the carer in this activity (Corbin and Strauss, 1985; Knowles et al., 2016; Vassilev et al., 2013). For several carers, the diary data also illustrated the work and time involved in co-ordinating the health and social care network as the disease progressed and managing the care-recipient within the home became increasingly more complicated. The carer's unique knowledge and understanding of the care-recipient, their condition, the context, and situation was vital as they negotiated and navigated across all aspects of the formal system.

Table 19: The Carer’s Role in Medicines Work [Dawit: Diary Entry]

<p>18.06 9am Movement Disorder Specialist (Consultant) Y Hospital</p>	<p>Face to face</p>	<p>Appointment attended with Zara. This was very important appointment with the specialist doctor who prescribed Apomorphine. I supported Zara to explain how she is doing with the treatment. I let Zara explain as much as possible where appropriate I intervened either to explain better, reinforce what she said or filled gaps in her explanation. The consultant reviewed and made changes to Zara’s medication (tablets – Sinemet and Amantadine)</p>
<p>19.06. 10 am District Nurse At home</p>	<p>Text</p>	<p>As agreed, I updated [District Nurse] of the outcome of the appointment with [movement specialis] and asked her when her next visit will be. She was driving to [county] to visit a patient and would get back to me to confirm either tomorrow or Monday. I texted back to say that is fine.</p>
<p>23.06. 11 am District Nurse At home</p>	<p>Face to face</p>	<p>[District Nurse] came to see Zara to check on her Apomorphin. Zara, and I updated her since we saw [movement specialist] who adjusted the medication by doubling Sinemet and stopping Amantadin. I stressed that Zara has lost the signs of improvement she had since stopping Amantadin. Her rigidity, slowness and freezing got worse as this could be side effect of stopping Amantadin. Talked about reducing it gradually rather than abruptly to minimize the side-effect. I said that we will be seeing [neurologist 1] tomorrow and that we will mention it. [District Nurse] also said that she would email [movement specialist] so that both doctors could liaise in regard to the stoppage of Amantadin. [District Nurse] will come back next Tuesday.</p>
<p>24.06. 10.10am 10.10 Neurologist 1 X Hospital</p>	<p>Face to face</p>	<p>I accompanied Zara to see [neurologist 1]. Zara was generally “on” when she saw the doctor but I had to explain that she was “off” in the last three days and that we think it is due to the abrupt stoppage of Amantadin. The doctor agrees that it would be better if it is gradual – hence agreed to reduce it to 50mg (from 100mg). She made a note for the GP. I will now need to make appointment to see the GP and get a new prescription. Zara asked [neurologist 1] if she could go on holiday during summer. She had difficult to articulate and I had to intervene to explain to [neurologist 1]. - saying that Zara wants to go to America</p>

Table 19 continued: The Carer's Role in Medicines Work [Dawit: Diary Entry]

24.06. Midday GP Receptionist At home	Phone	I phoned the GP receptionist to make an appointment with GP to get a prescription for change of medication. I spent a lot of time talking to the receptionist as they had computer change and was finding it difficult to find Zara's record. Finally, someone helped her to get the record. She wanted to give me appointment for 3 rd July but I had to explain the urgency and she said I could go tomorrow at 9am to give her a copy of the note from [neurologist 1]. She would discuss it with the GP who would get in touch with me over the phone.
25.06. 9am GP Receptionist Surgery	Face to face	As agreed, over the phone yesterday, I met the receptionist. She took a copy of the note from [neurologist 1]. She said she would present it to the GP and if needed she would contact me otherwise the prescription would be ready sometime today (?).
25.06. 930am Physiotherapist At home	Phone	Today Zara has appointment with [name] - physiotherapist at [centre] but she is unable to go as she has very bad rigidity affecting her right leg, right side of her body and neck. She is also very slow and shacking [sic]a lot. She said she is unable to go for her physio appointment at 10.10am this morning. I had to call [name of physiotherapist] and explain her situation. Agreed to reschedule appointment for 9th July at 11am.
25.06. 12.25pm GP Receptionist At home	Phone	GP Receptionist in regard to my visit in the morning. She confirmed that the doctor signed the prescription for Amantadine (50mg). I asked them if they could send it to X Pharmacy who supply Zara's medication and that I would collect it when it is ready.
27.06.14 11.30am Pharmacy (local)	Face to face	I went to pick up Zara's medication (Amantadin) from the local pharmacy but they told me that the medication is not available even with the manufacturer – they won't have it until August. That is not good. They said to try other pharmacies in case they have it in stock.
27.06.14 12.30 pm Pharmacy (Supermarket)	Face to face	I checked with [supermarket] Pharmacy. They confirmed what the local pharmacy said earlier. Both pharmacies advised me to check the hospital pharmacy so I went to the pharmacy at [Y] Hospital.
27.06.14 15.30pm Pharmacy (X Hospital)	Face to ace	Neither they have the medication – they confirmed the same as the other pharmacies. They advised me to contact Zara's Consultant who in the first place prescribed her the medication. The medication in question is Amantadin which Zara has been taking. The medication is now changed from 100mg to 50mg and it is the 50mg which is becoming very difficult to get. I will now contact the consultant next week.

7.7 Summary

In this chapter the role of both the health and social care sectors in shaping and developing the carers' social networks was presented. Considering these areas, the composition, shape, and utility to the carer were examined through the lens of linking social capital and Cantor's Social Care model (1979, 1991). The development of the health and social care sector was varied and dependent on the disease trajectory. PD is often a disease that progresses over a period of years and as such the involvement of the health and social care sectors can develop over time. However, as was apparent for some carers, sudden crises and deterioration led to a rapid iterative change. Access to care was varied and disparate. For a few carers privately paid care offered greater accessibility and range of provision as choice and control could be exercised. However, for others there was limited choice or control as the situation changed. In these cases, carers found other ways of attempting to exert some level of choice and control as they adapted to the changing dependency of the care-recipient, alongside their changing role and position at the formal/informal interface. The relationship with professionals and unqualified carers was important to facilitate the on-going management and delivery of care. Trust, respect, and carer recognition were all important components. Organisational structures and processes appeared to be resource-led not needs led. Thus, carers became frustrated, and conflicts and tensions were apparent from the carers' interviews and particularly the diary extracts. Their agency in bridging elements of the health and social care network, co-ordinating activity and, as brokers, sharing information to manage the care provided was evident. This was a demanding aspect of their role and often coincided with overall increasing demands for care as the care-recipient's condition worsened. As previously described in their role within the personal community, this network co-ordination demanded negotiation, required navigation, and harnessing of those individual resources available to the carer. Again, the carer drew on their personal resources, including their finances and individual attributes including their unique knowledge and understanding of the care-recipient's needs and their personal context of care.

Chapter 8 Discussion

8.1 Introduction

Utilising a case study methodology and social network approaches this study explored the social networks of 20 carers of a family member with Parkinson's Disease (PD). Social network data, carer diaries and interviews acted as complementary data collection methods that uncovered the utility and impact of these networks on the carers' role. This allowed for a panoramic view of the carers' networks that elucidated not only the structural aspects but gave a detailed and intricate account of the practices and interactions associated with the caring role.

The findings demonstrate that the carers are uniquely situated in relation to the networks of care that comprise the carers' Personal Community (the informal sector), and the state and the market in their role as providers of formal health and social care. The Third Sector (and particularly voluntary and community organisations, VCOs) acted as an intermediary between the informal and formal sectors. This sector was viewed as a *lifeline* by the carers, with the support offered acting synergistically with the health and social care provision. Caring for somebody with PD can have a prolonged and complex care trajectory. The study revealed that as this progressed the carers increasingly acted as network bridges, brokers, and co-ordinators which added to the 'work' of caring. As the carers navigated and negotiated across the various fields of care, the findings illustrated the complex series of transactional processes that carers must engage in to access assistance and support through bonding, bridging, and linking social capital whilst also drawing on other personal resources of economic and cultural health capital. These exchanges were facilitated by trust, respect, and mutuality. However, tensions, conflict and ambivalence occurred when expectations of support and recognition were not forthcoming.

This discussion will critically evaluate these findings and to do this it will be organised around the following overarching themes that were presented in the results chapters.

- The Personal Community: Bonding Together and Bridging Beyond
- The Wider Community and Third Sector Organisations (TSOs): Bridging and Connecting- *A whole new world has opened up to us*

- Health and Social Care Provision: Establishing and Maintaining Links
- The Carer as a Network Bridge, Network Broker and Network Co-ordinator

These themes will be expanded by considering social network theory, Bourdieu's definition of social capital (Bourdieu & Wacquant, 1992) and utilising a Bourdieusian lens to explore the various fields that comprise the informal and formal facets of the carers' networks (Bourdieu & Wacquant, 1992; Bourdieu, 2007). The informal and formal networks of support can be viewed as social fields. These spaces are structured by the networks that are contained within them. They are further shaped by the position of actors/individuals or organisations in the field. These relationships, with their respective positions of power, influence the transactional exchanges of resources (or capital) (Bourdieu and Wacquant 1992). The interdependency of relationships in these networks, their collective history, and the location of the carer in those relationships across the different fields are shaped by habitus (the general generative schemas or dispositions acquired over the life course) (Angus et al., 2005; Bourdieu & Wacquant, 1992; Bourdieu, 2007; Gilleard, 2004).

Each field where care took place had its own context and this influenced how carers interacted with those in that setting (Angus et al., 2005). For each carer direct personal biographical experiences, and experiential learning (Dannefer, 2003; Settersten & Gannon, 2005) can also intersect with the wider historical and social contexts over time giving rise to a 'generational habitus' (Gilleard, 2004; Crossley & Crossley, 2001; Moffatt et al. 2012). This reflects Bourdieu's (2007) consideration of culture and structure and their influence through periods of time or generational field, thus shaping individual dispositions and practices. The negotiations, practices and actions as situated in these fields will also be considered in relation to a macro perspective considering the evolving discourse of care and the socio-political and economic drivers of policy and care delivery. The unique features of the networks of those caring for a family member with PD will be discussed. Finally, the strengths and limitations of the study will be discussed alongside recommendations for professional education, and research.

8.2 The Carer's 'Personal Community': Bonding Together and Bridging Beyond

In this study the concept of the carer's 'Personal Community' (Pahl and Spencer, 2010) was used since it demonstrated the diversity and heterogeneity of each carer's relationships within and outside of their family networks. Thus, the support that was provided to the carers in their role was not limited to those identified as 'family' but to a wider set of relationships that incorporated, as proposed by Pahl and Spencer (2010, p.197) 'significant others...as a practical schema for capturing the set of relationships in which people are actually embedded.' As described by Sims-Gould and Martin Matthews (2007) informal care from the personal community was provided either directly to the care-recipient or indirectly through emotional, instrumental, and social support to the carer. The relationships in which the carers were embedded were varied with different degrees of commitment to the carer and care-recipient, and the use of network approaches in the study enabled those who were supportive to the carer in their caring role to be identified. Thus, it should be emphasised that the carers' networks were uniquely shaped by their individual biography and interdependency with others apparent across the network (Elder et al., 2003; Settersten, 2015). Therefore, a complex set of relationships that were inter and intra-generational and included friends, neighbours and acquaintances were uncovered. As identified by other authors, the relationships in this informal network were carefully balanced with complex interdependencies and shifts in power as the care trajectory progressed (Finch and Mason, 1993; Hillcoat-Nallétamby & Phillips, 2011; Connidis & Barnett, 2019; Corden & Hirst, 2011; Nolan et al., 2004; Fine and Glendinning, 2005). As the carers' role developed and evolved their position in the personal community altered and their interactions with the care-recipient and significant others in the network changed.

The networks were gendered with women predominantly identified by the carers in providing the social, emotional, and instrumental support they needed to care and those the carer might discuss their health with. This resonates with other work that has consistently demonstrated the dominant role that women play in care networks (Fast

et al., 2004; Finch, 1989; Finch & Mason, 1993; Twigg & Atkin, 1994; Ungerson, 1983; Ungerson, 1990, 2006; Yeandle et al., 2012). Although, the co-sanguineous family remained a central source of support for many of the carers, the increasing importance of friends in the carers' networks and their role in supporting the carer was clearly identified. Even though the carer network was captured over a relatively short timeframe the dynamic and evolving nature of the networks were evident (Kemp et al., 2013).

8.2.1 The Impact of Changing Demographics on Personal Communities, and the Informal Network

In examining this personal community from a Bourdieusian perspective it is possible to examine the unique network relations within this field and to consider how these relations structured the inherent bonding social capital. This bonding social capital and the resources contained within further shaped the transactional processes that occurred in the provision of care. Within this personal community the carers' habitus was socially and culturally situated. Thus, the practices and dispositions of the carers were determined by their social position in their personal community and the material conditions that the carer was accustomed to (Bourdieu, 2007; Angus et al., 2005). However, for the carers their social context was changing as the disease and the care trajectory progressed. Consequently, the complex interdependencies and relationships in the network shifted as their position and that of the care-recipient altered in relation to each other and those around them. Thus, the personal community as a field was evolving in relation to the changing demands of care. As the demands for care increased carers acted to draw on their networks for help based on their cultural and normative expectations of support that might be provided by those in the personal community. Struggles arose for some carers as they sought aid from members of their personal community, with conflict, tension and ambivalence arising when support was not forthcoming.

The structure and form of the carers' personal communities were clearly presented in the typologies that were uncovered in this study. These typologies identified the changing demographics of the United Kingdom, which were reflected in the diversity of the emergent family and wider friendship structures in each carer's personal community network. Thus, migration, increased filial distance from the carer and care-

recipient, divorce, re-marriage, and step-parenting all determined those who comprised the carers' informal network, the available bonding social capital and propensity for support (Keating et al., 2015). Geography therefore had an impact on the structure, form and interactions that occurred in the network. It is not surprising that the formation of care networks is more likely when individuals are in reasonable proximity and can travel. (Bell & Rutherford, 2013; Bowes, et al.; 2020; Dawson, et al., 2015). Thus, as might be expected propinquity was a key factor in shaping those who were most involved with support (and particularly instrumental support) of the carer on a daily or weekly basis. Increased filial distance from the carer/care-recipient certainly reduced contact and involvement in the care network by sons and daughters. Many of the carers with dispersed networks both nationally or internationally maintained these through information and communication technology. Therefore, in the 21st Century geographical distance did not necessarily preclude contact or the ability to obtain affective support. Although this was not ubiquitous across all the participants a variety of modes of communication were described by the carers, including the telephone, Facetime™, Skype™ and email. In this study the concept of networked individualism (Wellman, 2002), where individuals manage many varied networks that are not geographically bounded or based solely on kin structures through information and communication technology, may not be the case, given that the contact maintained in this way was, for all but one, with family. However, Carly was certainly managing several distinct groups through these means and particularly with her networks overseas. Geographically there was also a sense of physical spatial shrinkage of the care network (Egdell, 2012a). In this respect, several carers commented on how the PD progression was beginning to restrict travel, with life events in their siblings' (or in-laws) lives, also affecting face to face contact and therefore the overall availability and nature of support was altered.

Of those with children, only half of the carer-care recipient dyads had children who lived locally. Having children therefore did not guarantee carer support since associational contact (Bengtson & Roberts, 1991) was affected by geographical distance, work and family commitments and the affectual nature of the relationship impacted on the propensity for support.

In terms of this study there was a view of childlessness from two perspectives; that of the adult-child carer who was now caring for their parent and had no children of their own; and from the spousal carer perspective, where the couple had no biological or

stepchildren. Where the carer had no children (or stepchildren), they turned to others in the wider family. This was principally nieces and nephews who have been identified as important emotional ties for childless couples, offering generativity with a focus on one niece or nephew who maybe a future beneficiary (Wenger & Burholt, 2001). It is acknowledged that childlessness is not necessarily a negative outcome (Dykstra & Hagestad, 2007) although as was evident in this study it has implications for support in later life (Keating et al., 2015; Szinovacz & Davey, 2007). Patterns of childlessness in the 'baby boomer' generation shows that childlessness has increased from 9% of women born in 1946 to 18% of those born in 1968 (Berrington, 2017). As also highlighted by Szinovacz & Davey, (2007) these changes have implications for future policy as a significant number of the later generations of baby-boomers will have no biological children available for support. Childlessness for the adult child carers was also a contributing factor to their caring role which appeared to be gendered and path dependent reflecting their personal life course (Finch & Mason, 1993; Leinonen, 2011). Where stepchildren were part of the lives and informal networks of the carers, the quality of the relationships with stepchildren impacted on their caring role. There was an interesting dichotomy in the carers' relationships with these stepchildren. For Lenny where there was a close bond with his stepdaughters since they were classed as friends (Pahl & Spencer, 2004) and it was evident that that they were supportive of the carer and assisted his role whilst also giving direct help to their mother (Sims Gould & Martin Matthews, 2007). It was a different situation for Elizabeth. There appeared to be a difficulty in accepting their father's deteriorating condition and lacked propensity to support the carer. However, it has been noted that in the UK parental divorce has been shown to have little effect on the support and contact that adult children have with biological parents in their old age (Glaser et al., 2008) possibly because divorce is becoming more socially accepted in younger generations.

8.2.2 Carer Support: Family and Friends

In this study, as in other studies, the majority of the carers' networks comprised locally based family and friends with these connections providing a variety of support to the carers and care-recipients, representing the concept of bonding social capital (Ferlander, 2007; Halpern, 2005). Close kin, and in particular daughters, were key individuals providing emotional and instrumental support to the carer and care-recipient. This reflects the findings of other studies that have examined both care

networks and the networks of older people (Fast et al., 2004; Keating & Dosman, 2009; Lapierre & Keating, 2013; Phillipson, 2001; Sims-Gould & Martin-Matthews, 2007) and is aligned to Wenger's (1997) locally integrated support network. Within the study the significance of two distinct groups became apparent. These were siblings, siblings' in-law, and friends. Both groups had a high profile in many of the carers' networks and were key sources of principally emotional support. Improvements in lifespan for these carers meant that support was available for extended periods from those affective connections within the same generation (Silverstein & Giarrusso, 2010). It was apparent that the emotional support provided by siblings (and siblings in-law) did not necessarily require geographical proximity (Eriksen & Gerstel, 2002) but could take the form of regular telephone calls, emails and Skype™ activity. At interview, stories about current and past sibling relationships were shared and how companionship and emotional support (mitigating *loneliness* and *isolation* in Elizabeth's case), was now an important feature of the relationship. Siblings' in-law (and particularly sisters in law) were prominent particularly in the male carers' networks as they rallied round to support their ailing sisters. Studies of sibling relationships in later life have found that they can alleviate loneliness and the sharing of memories from a shared life course is important (Merz & De Jong Gierveld, 2016). For the carers and care-recipients these would constitute their oldest surviving relationships, thus the bonds were deep.

The involvement of the wider informal network for some of the carers was also evident (Fast et al., 2004; Feld et al., 2006) and the nature of support varied by participant. More limited instrumental support (compared to the support of close kin) was provided with social companionship and affective support given either directly to the care recipient or through assistance to the carer (Sims Gould & Martin Matthews, 2007). For many carers, friends were significant intimate ties and certainly played an important role in support of the carer and care-recipient. Friends can be long-standing, and the relationship can grow and develop over time without the constraints, tensions and ambivalence that might occur in family life (Pahl & Spencer, 2004; Allan, 2008). In the dispersed family and local friends' typology diversity in the network due to the impact of familial geographical distance was notable. Here, there was an emphasis on support from friends and in some cases, many varied friendships were identified (comparable to Wenger's (1997) wider-community focused support network). For several carers, their close relationships with friends offered family-like support with many supportive exchanges in the form of bonding social capital taking place (Allan,

2008; Ferlander, 2007; Halpern, 2005). Friendships had increasing significance for those carers who were migrants with family overseas and for those who were childless. Longevity also meant that long-standing friendships had offered support through much of the carer's life (Silverstein & Garrusso, 2010). Several carers were also instrumental in expanding their friendship network through activities in TSOs either throughout their lives or more recently. Extensive participation in community or carer and PD related organisations (as the PD progressed) had led to an expansion in the network and the increased availability of actual or potential support as found by Keating and Dosman (2009) and Roth (2020). This bridging social capital as originally described by Granovetter (1973) furthered access to community resources and certainly shaped the networks as friendships, developed and were cemented over time.

Across the informal network there became both a functional specificity (Simons, 1984; Perry & Pesosolido, 2010) and an experiential homophily (Perry & Pescosolido, 2015; Sutor & Keeton, 1997; Sutor, et al., 1995) in those alters who became significant to the carer in their role. Thus, where families were dispersed, close friends and those identified as having a 'bond' because of the PD diagnosis became especially significant in providing support. Suffusion of roles (Pahl & Spencer, 2004) was also described by several carers as friends were viewed as 'kin-like' in their relationships with the carer/care-recipient.

8.2.3 Bonding and Bridging Support: The Relational Dimensions

Within the personal community the habitus (Bourdieu, 2007) of individuals varies as each has their own unique biography. However, it is shaped by a collective generational history (Gilleard, 2004; Crossley & Crossley, 2001) and the interdependency of those who have shared biographies over many years, particularly of those associated with family and long-term friends. The developing friendships formed through the shared experience of PD with their mutual understanding of the disease and their shared carer identity also offered a collective habitus both generationally and as they journeyed on their caring trajectory together (Bourdieu, 2007; Elder et al., 2003; Settersten, 2015). Thus, the dispositions and practices in relation to care within this field that constituted the informal care network had characteristics and a common purpose that was broadly reflected across the group (Bourdieu 2007; Crossley & Crossley, 2001; Gilleard, 2004). Reciprocity and mutuality

in the relationships within the informal network were central to facilitating care and support for the carer. Reciprocity and mutuality are central tenets to the concept of social capital (Lin, 1999; Putnam, 2000; Halpern, 2005; Ferlander, 2007) and this was evidenced across all aspects of the carers' networks. Therefore care was not a unidirectional activity it was the outcome of the relationship between individuals (Bytheway & Johnson, 1998; Fine & Glendinning, 2005). Both those giving care and those receiving care were bound and implicated in the process (Finch & Mason, 1993; Ungerson, 2000).

In examining both the carers' informal network through the concept of a personal community as a field of practice (Bourdieu, 2007) it was evident that the relational dynamics of the interactions across this network of family and friends had an impact on their role and their perception of the actual and potential support available through bonding social capital (Cohen & Wills, 1985; Halpern, 2005; Thoits, 1985, 2011). This relational perspective placed the carer within a set of transactional processes that were dynamic and continuous, and therefore had a temporal dimension and could transform over time (Hillcoat-Nallétamby & Phillips, 2011). Within families intergenerational and cross-generational exchanges were apparent in the carers' relationships (Phillipson, 2001; Sims-Gould & Martin-Matthews, 2007). However, intergenerational exchanges were not unidirectional, and carers spoke of their care and support to their children and grandchildren through a variety of means, including financial support, instrumental support, and childcare. It has been recognised that demographic shifts and increasing demands for support to younger generations as state financial support diminishes has led to more older adults supporting and caring for not only those in their own generation but also younger family members in subsequent generations (Statham, 2011). Thus, within the family and in close 'family-like' friendship ties these were based on the history of the relationship and the cultural context within which the relationship was bound (Egdell, 2012b; Connidis & Barnett, 2019; Finch, 1989; Finch & Mason, 1993; Solimeo, 2009). The carer was cognisant of others' circumstances, particularly the commitments and responsibilities of alters in the network that might enable or limit their support with the caring role. Caring exchanges were manifestations of normative obligations that were formed over the life-course, a continuation of past relationships with a fluidity in the concept of dependence, independence, and interdependence of those in the relationship (Finch & Mason, 1993). This also resonates with the term 'nested dependencies' used by

Kittay (1999, p. 67) to illustrate the nature of relationships with the understanding that exchanges (in the form of care) may involve direct and immediate reciprocation or this may be delayed or transferred to others in the network. In this study the adult daughters recognised this long-view of care and responsibility for their parents and were clear about their commitments (Bengtson & Roberts, 1991). This was articulated by Caroline: *I look at it this way, my Dad brought me up and looked after me for years so you just...doing what it is right* [Caroline, interview].

Furthermore, within the family relationships, conflicts, tension, and ambivalence added other constraints and boundaries to accessing support as also described in other studies (Amaro, 2017; Carpentier & Ducharme, 2005; Hillcoat-Nallétamby & Phillips, 2011; Leinonen, 2011; Tolkacheva et al., 2011). The dynamics of the carers' relationships were bound to the wider interdependent networks of care that they were located in. As the caring trajectory unfolded the interplay of the social and cultural contexts of caring impacted on the relationships within the personal community thus altering the carer's position. For some carers this created a dissonance in their relationships leading to feelings of ambivalence (Connidis & McMullin, 2002; Luescher & Pillemer, 1998). For Tom and Elizabeth, the ambivalence arising in their relationships, in Tom's case with his daughter and in Elizabeth's case her stepchildren, were based on an expectation of support and recognition of their role as carers (mattering) (Thoits, 2011). Both were resentful at a perceived lack of recognition, and that support was difficult to secure, as this was counter to their culturally based normative expectations of support from the family. However, this was further complicated in Elizabeth's case given the non-lineage relationship. The commitment of adult stepchildren to a stepparent can be fragile as that parent ages. Thus, norms of solidarity appear weaker than those to older biological parents (Coleman et al., 2006) and may be reflective of a biography that has been temporally and spatially limited and therefore lacks interdependency. It is possible that in Elizabeth's case the stepchildren did not define her as a parent or even family (Schmeeckle et al., 2006) which may explain their lack of response to her needs as a carer.

Within this study carers were at different points in the caring trajectory (Aneshensel, 1995; Nolan et al. 1996). However, it was evident that for all the participants the evolving nature of caring and support impacted on the carers' relationships, leading to changes in expectations about the roles and responsibilities of the carer and others in

the wider network. Thus, relationships evolved as the exigencies of care unfolded and as others recognised and renegotiated (or not) their role in providing care and support. Ambivalence can occur where there are altering states of autonomy and dependence, with shifts in power from care-recipient to carer or from the carer to other family members, as individual roles alter with the evolving demands of care (Hillcoat-Nallétamby & Phillips, 2011; Connidis & McMullin, 2002; Luescher & Pillemer, 1998). Consequently, these challenge what were the established practices of the network and required a renegotiation of roles and support to balance these shifting dependencies. This supports the understanding that the fluidity and altered nature of 'family' life are evident in the practices, and identities that make up the changing relationships. Thus, how individuals interact and those fundamental shared understandings (that would emanate from a collective and shared habitus) of family obligation and responsibility are negotiated (Finch, 2007; Finch & Mason, 1993; Bourdieu, 2007; Gilleard, 2004).

In summary, the diversity and fluidity of both the composition of those in the personal community and the nature of the relationships within, were reflective of the carers' personal biographies and life-course (Connidis & Barnett, 2019; Williams and Keady, 2008) Thus, themes were germane to each carer and these through their impact on the structure and function of the network could be constraining or enabling for the carer in their role. These networks in their heterogeneity illustrated an emerging pluralistic and evolving model of 'family' with the potential availability and propensity of kin to provide care and support also changing. The changing demographics of family and social life was apparent through the interactions of carers with their family/stepfamily and friends across different generations. This highlighted a changing 'generational habitus' (Gilleard, 2004) as social norms and practices evolve over time and are a product of social and demographic change.

8.3 The Wider Community and Third Sector Organisations (TSOs): Bridging and Connecting: *A whole new world has opened up to us.*

At the meso level, the focus of this study was on the wider community and those intermediate structures (Evers, 1995) that incorporated TSOs (including VCOs). In Bourdieusian terms the organisations that comprise the TSOs can be viewed as a

social field that represent particular interest groups (in this case carers and care-recipients) and offer representation, solidarity, support, and self-help (Evers, 1995). TSOs are positioned in the public or civic space created between the 'cornerstones' of the other sectors (Evers, 1995, p161). When considered collectively these operate to provide a pluralistic model of care in the community. The habitus of this social field i.e., the strategies, practices and dispositions are structured by the ideology of each organisation and are reflective of the views and interests of the carers and care-recipients that are represented (Crossley and Crossley, 2001). However, TSOs are also influenced by the prevailing socio-political discourses and economic pressures that are present within social care. Thus, tensions can arise between providers in the 'mixed economy' of care as relationships alter between the different sectors and each must compete for economic resources whilst striving to maintain their values and individual ethos and habitus (Evers, 1995; Yeandle et al., 2012).

In exploring this social context or field, the resources that became available via bridging social capital (Granovetter, 1973, Burt, 1992) were evident. The findings of this study resonate with other work related to carers (Abendroth et al., 2014; Teahan et al., 2020; West and Hogan, 2020) and service users/patients (Jeffries et al.; 2015; Morris et al., 2015) involvement with TSOs. Roth (2020) also found that carers could develop networks that enabled them to bridge 'multiple social worlds' (p.278) when compared to non-carers and despite the restrictions in their life. Thus, for the carers in this study, joining a voluntary or community organisation uncovered an array of benefits that emanated from access, association, and participation in such organisations. The findings demonstrated that there was a blurring of the boundaries between TSOs, healthcare and informal care in their support of the care-recipients with PD. In this study, the mediating or intermediary role of the TSOs appeared to act as a buffer between the state, Government, and wider institutions such as health and social care (Evers, 1995; Moen & DePasquale, 2017). It has been argued that TSOs should be recognised as an aspect of civil society and therefore the role of these goes beyond just the service aspects of these organisations as they form part of the pluralistic delivery of care in the community (Baggott & Jones, 2014; Evers, 1995). It was apparent that these organisations offered a further dimension to care, and their role was both supplementary and complementary to the state and market provision. In this study they appeared as an independent and separate space or field for carers and care-recipients to associate and participate which facilitated the development of

wider friendship networks (Bourdieu, 2007; Bowlby, 2011; Evers, 1995) and enabled bridging social capital. This also resonates with Putnam's work on the communitarian aspects of social capital and how a vibrant civic society promotes and develops the social capital of individuals, communities and nations (Putnam, 2000). However as already described, within the field of health and social care delivery, TSOs must compete for economic resources to maintain their viability and concerns have been expressed that overuse and underfunding and support for TSOs is decreasing social capital in this sector (Humphries, 2011; Humphries et al.,2016). The funding restrictions due to austerity were noted by Carly in her interview and what this had meant when a local carers' hub had lost much of its funding, meaning that its's work across the area with carers was curtailed. For Carly, and others that she knew, the resulting reduction and fragmentation of these carer services had drastically altered the quantity and quality of local carer support.

Within this field of organised community-based groups, their *raison d'être* shaped the habitus. As noted by Evers (1995), within this realm the support networks managed to balance uncoerced association given that membership was voluntary, but within a formal organised structure (thus aligned with a publicly provided services), and with an emphasis on personalised relationships. The orientation and alignment to the needs and situation of the carers and those with PD was integral and evident at the meetings and groups visited. Each voluntary or community organisation was structured with a focus on the social support of the carer and/or the care-recipient. Organisations with a particular association such as Parkinson's UK or carer issues further shaped their ethos, practices, and dispositions therein (Crossley & Crossley, 2001; Bourdieu, 2007). Their non-judgemental inclusive ethos facilitated solidarity and bonding. As previously described (see chapter 2, section 2.3-2.5) PD has many overt signs of illness and disability which can be stigmatising for the care-recipient and carer and induce a sense of shame (Caap-Ahlgren *et al* 2002; Schrag *et al* 2003; Soliimeo, 2009; Nijhof, 1995). In this study carers such as Debbie expressed their embarrassment about the disease. In Adam, Margaret, and Harriet's cases their fears of disability and for the future were evident as they and the care-recipient contemplated their 'biographical disruption' (Fairclough et al.,2004; Charmaz, 1995; Bury, 1982; Pinder, 1992) associated with the diagnosis of a long-term condition. The hesitancy in joining the groups and similar feelings of embarrassment and stigma was also highlighted in Lauritzen's et al, (2019) study. Similarly, the importance of the

ambience of the group and community ethos was also described by Teahan et al., (2020). The acceptance of those outward stigmatising signs of the disease was therefore important and this facilitated access and entry.

Online information and forums offered an entry point into this social space. This was particularly relevant for Carly and Mary and was discussed by several others. The habitus of this online platform offered anonymity which was needed due to stigma and uncertainty (Rasmussen et al., 2007). Research has underscored that the connections made in the online forums also offer empathy as experiences are shared (Hargreaves et al., 2018). It can be argued that the online groups are themselves social fields with a prevailing habitus. Certainly, building trust in the online forum with those involved is an important element of engagement (Lovatt et al., 2017), and as Mary found, poor online experiences can quickly deter access. There is a growing interest in how digital literacy and online use might aid carers in their role. Internet use has been found to be associated with and shaped by the number of hours spent caring, age, sex and employment status and these factors can lead to a digital divide in access (Blackburn et al., 2005). Dependent on the nature of the group (disease specific versus carer-related), the decision to join a voluntary or community organisation was not necessarily a sole decision for the carer and at times required careful negotiation with the care-recipient further demonstrating the inter-dependency of the relationship (Fine and Glendinning, 2005; Kittay, 1999; Finch and Mason, 1993; Brossard & Carpentier, 2017; Egdell, 2012b; Egdell et al., 2010; Pickard, 2010). Thus, the process of entry and timing into the groups as found by West and Hogan (2020) was critical with 'readiness' of the care-recipient and carer needed to take this step.

These organisations certainly demonstrated an intermediary role, between the informal sector (i.e., carers, their care-recipients, and their families) and formal health and social care services. Critically they brought together a range of resources for carers that were viewed as a *lifeline* in support of 'illness work.' This filled a gap for the carer (and carer-recipient) in terms of specific needs and support that was not available from the state or market sectors (through the formal health and social care routes). Thus, in this aspect there was a synergy in the provision rather than a straight substitution of services (Evers, 1995). In Abendroth et al.'s (2014) study the concept of a lifeline was also proposed, in relation to the support obtained from peer-led groups for carers of those with PD. However, this concept was used in a more limited context and specifically focussed on the carers support of others in the group. The findings in

this study are more detailed and wide-ranging. They certainly demonstrate how these organisations facilitated widening access to a wealth of support and opportunities. Thus, on joining the groups, the carer and care-recipient did not necessarily fully understand the future benefits. However, as Carly and others found a whole new world had 'opened up'. This transition into the world of TSOs and in the context of this study, particularly Parkinson's UK and other carer-related organisations, gave accessibility to potential new network ties. Although activating support through this route was deliberate by the decision to join and engage with the groups, developing new ties (as was the case when Carly met Mary at the carers' support day, (see chapter 3, section 3.8) could also be 'incidental and spontaneous' as the accessibility afforded by participation offered unexpected opportunities for support and new experiences (Small & Sukhu, 2016, p. 73)

8.3.1 Bridging Support: Developing Cultural Health Capital

The ties that were formed initially to the groups and then more specifically to members within the group(s) facilitated access to potential and actual bridging social capital that enabled access to a range of resources and opportunities as described by Granovetter (1973; 1984) and Burt (1992). As Roth (2020) also found, this ability to form these bridges and thus expand their network appeared to be a feature of their transition into the caring role. The support and benefits that membership conferred were viewed by the carers in this study as a *lifeline* in the caring role. The benefits identified were not only through access to bridging social capital but also through the development of cultural health capital (Shim, 2010). Shim (2010, p.3) defines this as 'a specialized form of cultural capital' that can be leveraged in health care contexts to effectively engage with medical providers and achieve successful health outcomes (Abel & Frohlich, 2012). It is acknowledged that the social and historical context will determine the precise form that cultural capital/cultural health capital will take (Bourdieu, 2007; Shim, 2010).

In healthcare, there has been a changing discourse with an increasing emphasis on self-management and self-efficacy in managing long-term conditions such as PD. To navigate increasingly complex health and social care systems, and effectively access health resources, carers and care-recipients need to be able to communicate with health professionals and understand, assimilate, and apply complex health information (Allen, 2000; Shim, 2010; Wilson, 2001; PHE, 2015). As the carers in this

study became established in the group it was evident that the sharing of knowledge, skills and understanding led to effective peer support as described by Vassilev et al., (2011, 2013, 2014) and Morris et al., (2015). Activation of ties in the group served to facilitate health specific conversations that the carer and care-recipient found to be informative, sympathetic, and helpful (Perry and Pescosolido, 2010). Furthermore, as described by some of the carers, decisions on care provision and treatments were sometimes based on recommendations by those in the groups as they shared experiences of different hospitals, Consultant care, treatment options and medicine regimes. This study also highlighted the clear development of additional 'bridging' contact with professionals and others with specialist knowledge (such as the Information Support Worker (ISW)) which has not been described in other work. These specialists also enabled the carer to support and manage the work involved in dealing with a progressive long-term condition. As relationships developed, they enabled the carer to contemplate and examine their role, through social comparison with others and through gaining more information and understanding of the disease (Morris et al., 2015; Thoits, 2011; Vassilev et al., 2011). Social comparison and the influence of those in an individual's reference group were identified in the 1950's by Merton (1957) (cited in Christakis and Fowler, 2009). The power of this ability to influence individual attitudes, beliefs and behaviours via social networks is gaining greater interest as online networks become ubiquitous and the power to shape health, illness and other behaviours across a network becomes more understood. Although previously it was considered that social influence and comparison in terms of their effects on health behaviours had been overlooked (Christakis & Fowler, 2009).

Individuals use comparisons to manage uncertainty, to be able to cope more effectively. The carers in describing their interactions within the carers and Parkinson's UK groups discussed social comparison as they assessed their own situation and that of others. This appeared to facilitate a reflexive narrative, that sought to assimilate the processes of ageing and the disease progression associated with PD, as a means of understanding the illness within their own biography (Faircloth et al., 2004; Solimeo, 2009). Observations and interactions with others in the group were described by the carers during the interview. Margaret discussed her thoughts about the deteriorating health of one individual, she knew at the dance group which was an example of a downward comparison when compared to her husband. Henry also discussed how comparing his and his wife's situation offered a means of making sense and

reassurance about their position with the illness. Upward comparisons, also allow comparisons with people who are faring better and this encourages information seeking and reassurance (Taylor & Lobel, 1989). Other studies in relation to carer burden and coping with PD have commented on this as a means of coping with the condition (Williamson et al., 2008).

In this intermediary social space bridging social capital was apparent as peer support developed with social exchanges that facilitated socialization and acceptance (Abendroth et al., 2014; Vassilev et al., 2013; West & Hogan, 2020). This support, and interaction allowed the transmission of cultural health capital across those members of the group. The findings add to the growing evidence on the impact of health-related support networks in relation to long-term conditions such as mental health, diabetes mellitus and chronic kidney disease. These benefits are an outcome of the normative influences of the group, with shared perceptions, objectives, efforts, and beliefs, that help to guide members' attitude to and management of their condition thus promoting collective and self-efficacy. (Perry and Pescosolido, 2010; Vassilev et al., 2014; Crossley & Crossley; 2001)

8.3.2 Bridging Support: The Relational Dimensions

These groups offered experiential homophily (Suitor and Keeton, 1997; Thoits, 1986) although there was a heterogenous mix of individuals involved with inclusion of others such as professionals and support workers. Experiential homophily facilitates activation of social ties in relation to health and care-networks as previous work has indicated (Perry & Pescosolido, 2015; Suitor & Keeton, 1997; Suitor et al., 1995; Thoits, 1985). This study found that the development of deep, lasting relationships that were formed in the groups were an essential feature of membership as has been previously described (Abendroth et al., 2014; Lauritzen et al., 2019; Teahan et al., 2020). Finding and making new relationships within these groups was discussed by many of the carers. As in Abendroth's (2014) study they valued sharing their experiences with others and the resultant emotional support (Lauritzen et al. 2019) was beneficial for both the carer and the care-recipient. The relationships formed with those in TSOs and particularly those voluntary or community-based organisations that offered either carer specific support or a disease related focus for support were voluntaristic. Thus, the development of relationships within these groups were mutual

and not necessarily constrained by past histories or normative expectations or obligations usually associated with families. Debbie, Caroline, Carly and Gary in their discussions about the groups all commented on the carers and care-recipients ease with those in the groups. Here, the relationships were devoid from the stigma associated with a chronic illness experienced through interactions in the everyday world (Solimeo, 2009). The developing and established friendships were mutually agreed with a shared understanding of the carer's role and their day-to-day experiences of living with PD.

An interdependency between those in the group developed as the friendships evolved. However, in this respect autonomy and dependence were not salient features but reciprocity and mutuality of support were important in these relationships (Halpern, 2005; Ferlander, 2007). Thus, the relationships within this field did not exhibit power differentials but were co-operative. This was evidenced in Adam's diary as he noted the support, he was offering to a fellow male carer at their Parkinson's UK meeting. Reciprocity and mutuality were also apparent as carers became more active (principally in Parkinson's UK and carer groups) by helping to organise the group's activities or in Carly's case becoming an advocate for carers and the organisations that represent them. Thus, these groups gave the carers' a voice and a means of expressing themselves within the group and to wider audiences (Crossley & Crossley, 2001; Yeandle et al., 2012). This type of involvement promoted self-esteem and worth (Thoits, 1985, 2011) and a sense of giving something back (*I'm able to help other people and that's a good thing*, Adam interview). Those most involved in organising and managing these groups (Debbie, Adam, and Denis) also utilised skills developed in their working lives.

To summarise, this study demonstrates the intermediary role of the TSOs as they brought together a range of resources for carers that were viewed as a *lifeline*. This acted synergistically to provide support that was not available from the state or market sectors. The findings in this work clearly demonstrate the role of TSOs in supporting the development of bridging social capital for carers (and care-recipients). This bridging social capital also aided the development of the carers' cultural health capital through access to information, knowledge, and experience, aiding carer (and care-recipient) self-efficacy in managing the progressive nature of PD. This also supported

carer well-being and potentially facilitated and guided carer decision making in their role and in supporting illness work.

8.4 Health and Social Care Provision: Establishing and Maintaining Links

In examining the role and position of the health and social care sectors several factors that affected the supply, demand, and access to services as described by Fotaki (2010) were uncovered. There was a complex interplay of factors within this 'field' of formal care delivery. This consisted of structural factors, the conflict of the habitus of the field of health and social care with that of the carers, alongside the agency of the carer as they utilised personal resources to navigate and negotiate across the network to seek and obtain the care and support that they required.

The provision of care and support from the health and social care sectors can be viewed as public goods (Evers, 1995) with access to care obtained via linking social capital (Szreter and Woolcock, 2004), as individuals interact across formal institutions with different professional groups. Thus, within the fields of health and social care there are many different relationships and varying power gradients (Collyer et al, 2015; 2017; Angus et al.,2005; Szretzer and Woolcock, 2004). Furthermore, the habitus of the formal sector also shapes those interactions and practices that are deployed by health professionals and paid healthcare support workers (Twigg, 1999; Angus et al., 2005; Barnes, 2012).

Those that work within the fields of health and social care can act as gatekeepers in terms of the allocation of resources, through referrals and access to other services and as conduits of knowledge and information (Fotaki, 2010; Collyer et al., 2015, 2017). Within this study the role of linking social capital as described by Szreter and Woolcock (2004, p.650) in terms of 'those that connect people across explicit 'vertical' power differentials, particularly as it pertains to accessing public and private services that can only be delivered through on-going face-to-face interaction' was examined in the context of the experiences of the participants caring for somebody with PD. The power differentials within the encounters that carers experienced in the systems of care were described as they recounted accessing care for their relative and working with providers. As previously described by Collyer et al. (2017) and Shim (2010) the

role that cultural health capital and economic capital played within the complex fields of health and social care became apparent in terms of the choices that could be made by the carer (and care-recipient) in terms of care and the options that these forms of capital afforded. By further applying Bourdieu's concepts of habitus, capital and field (Bourdieu and Wacquant, 1992; Bourdieu, 1986; Bourdieu, 2007) it was evident that these different forms of capital shaped the care trajectory, the development of the network within the formal sector and the experiences of care.

Furthermore, those practices associated with the carer's habitus and their social field were 'superimposed' with the fields of health and social care and the practices and dispositions associated with those domains (Angus et al., 2005, p.161). In this study, this gave rise to tensions and conflict as the carers' practices and knowledge of caring for the care-recipient were questioned, altered, or disrupted by health and social care providers. It has been found that experienced carers can be viewed by health professionals as a challenge to the social organisation of care delivery, in relation to care processes, the professionals' knowledge and expertise and the set standards of care (Allen, 2000). To achieve access to the resources needed for care, the carers recounted their navigation across the various domains where care took place (home, hospital, and the community setting) (Egdell, 2012a, Angus et al., 2005) whilst negotiating their role and the requirements of the care that was needed. In this study, the role of professionals acting as gatekeepers to resources for the carer and care-recipient was highlighted and the care relationship with qualified and unqualified professionals was a central feature in the successful navigation and negotiation of care.

8.4.1 Establishing Links: Disparate Routes to Formal Care

Within health and social care being able to exercise choice as a patient or carer about the type of care provision is socially structured (Collyer et al., 2015, 2017; Yeandle et al., 2012; Crossley & Crossley, 2001). Thus, the prevailing habitus within the fields of health and social care and the interaction of different forms of capital (particularly linking social capital, economic capital, and cultural health capital) gave rise to various dynamics within the formal care sector that subsequently shaped the carer and care-recipient's access to those who determine the treatment and care options and those who provide the care (Collyer et al., 2015, 2017; Yeandle et al., 2012; Shim 2010). Establishing links with the publicly funded formal network was difficult for many carers.

Disparate access was compounded by mechanisms of referral, geographical location, and fragmented/variable service design (Fotaki, 2010). The problems and difficulties relating to the complexity and heterogeneity of services for those with PD have been recognised (Parkinson's, UK 2019; NHS England, 2019c) and improvements are needed to integrate care and to ensure wider access to specialist services. This disparate access of support for carers and care-recipients with progressive neurological problems has also been found in other studies particularly in relation to Alzheimer's disease and dementia (Egdell, 2012a; Carpentier, Ducharme et al., 2008; Carpentier, Pomey, et al., 2008). The structuring of any formal support will vary and be influenced by the choices made by the carer and care-recipient alongside the availability and eligibility of services that can meet the needs of the care-recipient and carer (Carpentier et al., 2010; Carpentier, Ducharme et al., 2008; Carpentier, Pomey et al., 2008; Egdell, 2012a; Hong, 2009). Within this study the role of health and social care professionals as gatekeepers (Collyer et al., 2017) to different care resources was apparent with their decisions shaping the subsequent choices available to carers and care-recipients. Linking social capital was disrupted or absent for several reasons as follows: where services were fragmented, or organisational and structural constraints made access difficult for the carer and care-recipient (Dawit and Susan highlighted some of the difficulties associated with the specialist PD unit that they wanted to access); when referral or access was not facilitated or enabled by a professional; or where means testing, and assessment criteria impacted on eligibility for services. The latter two points were particularly evident in the carers' access to respite (in the case of Tom, Susan, and Gary). Those carers who were most successful in obtaining the resources and establishing effective links with health and social care providers, were those with the resources that could be deployed within these fields to their advantage.

The marketisation of health over the last 30 years and the evolution of pluralistic care provision has altered the relationship of carers and care-recipients with their health care-providers (Glendinning, 2012). Collyer et al., (2015: p.96) comments that healthcare is more of a 'maze' than a system. This was apparent in this study, and it could be argued that this was also the case for social care. For carers and care-recipients to effectively navigate these fields required access to appropriate and sufficient individual resources. It was evident that those who could draw on their personal capital/resources and particularly their social capital, economic capital, and

their own cultural health capital (Halpern, 2005; Bourdieu and Wacquant, 1992; Shim, 2010; Collyer et al., 2015) were able to manoeuvre more easily through the system and seek out the care and support they desired. In the carers' accounts of those who had described the skills and resources they had used to navigate the healthcare system, the intricate links between social and cultural health capital, and personal finances were apparent.

As described in section 8.3 an interesting synergy was also uncovered in terms of the cultural health capital gained through engagement and participation with the TSOs and particularly Parkinson's UK. In their formal interactions with health and social care professionals some of the carers and the care recipients (Adam and Monica were examples) explicitly used their cultural health capital, particularly in relation to their medical knowledge and understanding of PD. This was gained through their previous education, professional qualifications and experientially through the care trajectory. Seeking out information via the online forums and at the Parkinson's UK meetings was also a valuable means of extending the carers' cultural health capital. The use of personal bridging social capital was evident in Susan and Monica's case since they had personal contacts in the medical field. Financial resources determined access to private care (which will be discussed in 8.4.3) and for some this was certainly a significant means to accessing the care and resources that were timely and, in their opinion, the most appropriate, and of a high quality.

8.4.2 The Interface of Informal and Formal Care in the Home Setting

For each case, where home care was delivered, the changing condition of the care-recipient had necessitated regular homecare since the demands on the carers had become excessive. There was little choice for the carer or care-recipient in having to accept care if the care-recipient's condition was to be managed at home, which was the preference for the carers and care-recipients in this study. The accounts from Debbie occurred in real-time as the data for the study was being collected. In the discussion with both Debbie and Susan it was evident that the sudden introduction of domiciliary care had left them feeling powerless with a loss of authority over the timing of care and how that care proceeded. Although the discourse of health and social care delivery emphasises choice and control in the delivery of services with carers and care-recipients viewed as consumers of these services (Fotaki, 2010, 2014) the reality of the service meant that it was difficult to negotiate timing and to obtain guarantees

on which health care support worker or paid carer might be allocated. Although they were not the employers, as found by Sims-Gould and Martin-Matthews (2010) the carers found themselves managing care delivery and the monitoring of care quality and could be viewed as co-workers (Twigg, 1989; Twigg & Aitken, 1994). Accounts of the entry of other carers into their home could be difficult and threatening as the social space of the domestic field was changed and their authority within that space was altered (Twigg, 1999; Angus et al., 2005). Furthermore, the entry of domiciliary care also marked a change in the carer/care-recipient relationship. The interdependency of the dyad that existed in the home setting of these spousal carers and was shaped by their shared habitus was shifting as the dependency and independency within the dyad altered (Connidis & Barnett, 2019; Fine & Glendinning, 2005). The decisions to introduce domiciliary care were difficult and the required negotiation with the care-recipient was delicate, particularly in Debbie and Susan's case where the changing cognitive status of the individual, and a sudden decline had precipitated a crisis. These difficult negotiations have been described in other studies (Egdell, 2012a, 2012b; Egdell et al., 2010; Groen-van de Ven et al., 2018). For those with dementia or cognitive changes, as mental capacity fluctuates or is deteriorating, there is an added complexity to the tripartite approach (between the carer, care recipient and providers). The dilemmas they faced required sudden changes to the networks of support and had heralded further 'biographical disruption' (Bury, 1982; Stanley-Hermanns & Engebretson, 2014). These changes needed to be assimilated and reconciled as the situation unfolded. For each carer the social context of the situation was unique and complicated as different professionals entered the care network, the manifestations of the disease were quickly evolving, and personal biographies and resources needed to be managed (Charmaz, 1983, 1991; Solimeo, 2009). Aasbø et al (2016) have described the concept of 'biographical we' as carers strive to maintain a balance of independence and integrity for themselves and the care recipient whilst also ensuring the safety of the care-recipient and managing the progression of the disease. In this study, the spouses described their great efforts to re-establish normality and continuity in their everyday lives.

For Susan and Debbie, their accounts of the introduction of domiciliary care illustrated the impact of a changing power dynamic as they relinquished care of their spouse to formal providers (Susan: *you know I cried so much...I thought. what is this woman doing washing my husband?*). In Debbie's case the changes occurred as the study

was being undertaken. Thus, at the interview the transitional arrangements to home care were still underway and the logics and practices (Angus et al., 2005; Twigg, 1999) of the health and social care provider were beginning to impact on her home. The nature of home with its cultural, and biographical history represents a social field and reflects a personal habitus (Twigg, 1999; Angus et al., 2005; Bourdieu, 2007). These changes to the home gave rise to conflicts and tensions as the various practices normally associated with the home were over-turned by the ensuing practices associated with the fields of health and social care providers. Thus, in Debbie's case, and as described by Angus et al., (2005, p172) in a study of homecare provision in Canada, the home became a 'contested space' as carers raised concerns about the impact on the aesthetics of the home, as equipment was introduced, and alterations made that were required by the providers to manage care provision. Conflicts also occurred on the timing and nature of the care routine and, in reference to how the cleanliness and order of the home should be maintained. Each carer who received domiciliary support described the disruption of changing routines, when multiple carers were used or when carers were late or missed appointments. Thus, there was alterations in the spatial, temporal, and social dimensions of the carers field i.e., their home, that required navigation and negotiation by the carer.

8.4.3 Extending the Formal Care Network: The Position of Private Care

This study offered a window into the development of a network of formal care that included or was substantially provided by private healthcare and in two cases privately arranged social care. The personal resources of some carers meant that privately paid care offered a bespoke, accessible alternative. In this respect the carers' personal resources i.e., economic capital ensured access to a range of healthcare and personalised domiciliary care. The situation for Elizabeth and her husband was unique in the extent to which they utilised private healthcare. The decision to purchase healthcare demonstrated an intricate relationship between the carers (and care-recipients) beliefs and social ideals as developed during their life course and manifest in the habitus (Collyer et al., 2015; Shim, 2010; Angus et al., 2005. Thus, their developed health and cultural beliefs, their perceptions of the likely benefits and risks, and their expectations (in terms of control and autonomy) in the choices that they could make all played a part (Fotaki, 2010). This incorporated a view on care as a commodity that can be bought to ensure quality and their ability to exercise choice in their

decisions about those involved in care, alongside the timing and place of care. Thus, the dynamics and relationship between the field of healthcare, the carer's habitus and those capitals employed were apparent. In this group of carers, four spoke openly about their arrangements in terms of private healthcare. Thus, in these cases, when entering the field of private health, the rules of engagement based on monetary exchange and the positions of each (professional, carer and care-recipient) within that field were altered when compared to that provided in publicly funded care.

Also captured in this study were two privately paid domiciliary arrangements. One was supplemental to the Local Authority (LA) provision and the other was a paid arrangement between Elizabeth and her brother (see chapter 5, section 5.3.8). These arrangements therefore circumvented the constraints and limitations of regular formal provision. The introduction of a family member caring for Elizabeth's husband did not have the same impact on the habitus as described by those receiving formal domiciliary care. However, in Susan's case, this private arrangement meant that the delivery of care and logics of the healthcare field was reconstituted. Thus, as this arrangement became established the relationship between the carer and the healthcare support worker became more personalised as recounted by Susan (see chapter seven, section 7.4.1).

Susan: She is...she's like a friend...in fact recently she's called me her mum...so...coz her mum's in [name of country]... ..and she's patient, she's kind, she's caring, she's jovial...she's...she's everything you could want in a carer...

The direct employment of the carer, therefore appeared to shift the dynamics of the field and the relationship between the carers. For both, there was a change in their status and autonomy. For Susan and her husband this gave them greater control in the timing and nature of the care that was to be provided separate to the usual constraints of working with a contracted service. Furthermore, the organisation and logics of their home as a field of care could also be directed and controlled by them. For Precious (the paid carer), this gave her flexibility in her working conditions, free from the contracted homecare provider. Angus et al., (2005) has described how improvisatory practices may be employed by care recipients and local homecare

providers to facilitate social exchanges and recognition and bond relationships. However, in this case these arrangements were more substantive and completely circumvented what might be viewed as the deficient provision provided through the regular formal sector.

Glendinning (2012) has argued that constraints on the funding of public sector care and the marketisation of the sector are leading to a reduction in publicly funded social care delivery with an increasing role for a private supply with private funding. This shifting of care delivery from the publicly funded sector to the private sector is highlighted in the study, although the carers were not utilising the direct payments or personal budget system associated with the personalisation agenda. Each carer who discussed their use of private care emphasised their position as fortunate in that they had the economic means to be able to purchase care. However, this was contrasted by those carers who felt that the publicly delivered systems were resource-led not needs-led, and they were being denied access to the services (particularly respite) they needed (Humphries, 2011; Humphries et al., 2016; Fotaki, 2010, 2016).

Reflected in these findings is the increasing role of private provision and the changing discourse on choice and autonomy in accessing healthcare. This has added to a change in service users and carers attitudes to expectations, availability, and suitability of services (Fotaki, 2010; Yeandle et al., 2012; Collyer et al., 2015; Glendinning, 2012; Rodrigues & Glendinning, 2014).

8.4.4 Linking Support: The Relational Dimensions

It has been argued that in the realm of the market provision of health and social care the most central dimension of care that is overlooked and absent in policy is the quality of the relationship between the service user, informal carer, and paid carer (Lewis & West, 2014). The rhetoric of the market over the past 30 years and consumer-led approaches to the provision of health and social care have tended to neglect the importance of the process of care and the significance of the role and attributes of the practitioner (be it qualified or unqualified) in providing high quality care. In other studies that have examined the interactions of carers with the formal network of support have also stressed the importance of developing co-operative, and collaborative relationships to enhance partnership care (Sims-Gould & Martin-Matthews, 2008; 2010; Carpentier and Grenier, 2012; Groen van de Ven et al., 2018; Jaglal et al., 2007). Furthermore, being attentive and responsive to individual needs and meeting

the preferences of the service user (and carer) facilitates the development of the relationship (Rodrigues and Glendinning, 2014; Tronto, 1993).

At the interface of the social worlds of informal and formal care it became apparent from the carers' accounts that the relationships that developed at an intimate and personal level facilitated a collaborative and cooperative approach to care. The quality of these relationships was as important with qualified practitioners as they were with care support workers/unqualified formal carers. Thus, the value placed by the carer in the personal attributes of attentiveness, kindness, and compassion aligned with a moral or ethical view of care (Tronto, 1993). Carly when discussing her and her husband's relationship with their GP highlighted these principles. Others have noted the significance of interpersonal skills (Spiers 2002) and the need for social etiquette when providing care in the home (Piercy and Wooley 1999). Rodrigues and Glendinning (2012) in examining home care delivery found that older people valued being able to develop relationships with their regular paid carers. In this study, where regular paid carers became part of the domiciliary care delivery, their input and growing understanding of the care situation was important and highly valued by the carers. Susan's case particularly highlighted this as she had developed a close and facilitative relationship with her husband's carer. This also highlights the micro and meso-perspective of care as the field of informal care intersects with the fields of health and social care (Rodrigues & Glendinning, 2012; Daly & Lewis, 2000; Angus et al., 2005). As described in the literature review, 'caring about' an individual is integral to care work and cannot be readily commodified or legislated which has been the thrust of social policy (Tronto, 1993; Barnes, 2012). The nature of the care relationship helps to define the care provided and shapes the individual's experience of care (Twigg 1999).

Care quality in the formal, paid sectors has been recognised for some time as being potentially problematic, and recognising the collaborative nature of social care, and the part that the caring relationship plays in formal provision is a requirement to ensure service quality (Donabedian 1988; Malley & Fernandez; 2010). Unfortunately, commissioning tends to focus on the outcome measures of care such as the time taken and the tasks to be performed and thus fails to recognise the emotional labour required to provide care (Smith, 1992, Tronto, 1993; Lewis and West, 2014). The importance of acknowledging the carers' role and offering support to the carer (not only the care-recipient) as they managed the complexities and responsibilities of

caring for their partner or parent was highlighted by several carers as they discussed their involvement with the formal sector. At times, as described by Aasbø et al. (2017), this required negotiation to maintain a cooperative relationship. This work also reiterates the findings of others (Sims-Gould & Martin-Matthews, 2008; Carpentier & Grenier, 2012). Trust and mutuality are integral in the relationship between care providers and carers/care-recipients. Therefore, understanding the facilitators and barriers to the development of trust and mutuality with carers and care recipients remains important in health and social care practice.

Within the formal care sector these findings have demonstrated the interaction of different forms of capital (particularly linking social capital, economic capital, and cultural health capital) that shape the carer and care-recipient's access to resources. Establishing links with the publicly funded formal network could be difficult with disparate access compounded by mechanisms of referral, geographical location, and fragmented/variable service design. The role of gatekeepers in facilitating access to care resources was also apparent. Fragmentation of services alongside organisational and structural constraints meant linking social capital was disrupted or absent. The development and utilisation of cultural health capital was evident in some carers accounts and facilitated access to resources in the formal network. For those carers that had the financial means to obtain care this consumer choice meant that they could control and bespoke their formal care network. The relational dimensions of the encounter between the carer and the professional, or care provider was significant in enabling collaboration and partnership and assisting the carer in their role.

8.5 The Carer as a Network Bridge, Network Broker, and Network Co-ordinator

The findings in this study particularly highlighted the carers' role as a network bridge, network broker, and network co-ordinator as they traversed the informal and formal care networks. This has not been explicitly considered in other studies. This final section, therefore, explores how the carers' achieved these roles through navigation

and negotiation across the various 'fields' (Bourdieu and Wacquant 1992), that comprised the informal and formal domains of care. The detail elucidated from the data gave a panoramic view of the carers networks. From this network perspective it became evident that extensive navigation and negotiation was required across the full gamut of their care networks. This illuminated the complexity of the carers' role and the 'work' involved in orchestrating their network to garner assistance and support. Although the concepts of navigation and negotiation have been previously examined in relation to the carers' role (Finch and Mason, 1993; Egdell et al., 2010; Egdell, 2012b; Aasbø et al., 2017; Allen, 2000), here they are applied directly to the overall management and co-ordination of the network.

As described by Granovetter, (1973; 1983) bridging ties support flows of information and ideas across or between groups and those who occupy 'structural holes' within networks can 'tie' or link separate social networks (Burt 1992). These individuals are often pivotal in the transference of information and ideas across a diverse group (Long, et al., 2013; Prell, 2012). The role of TSOs in enabling the carers to access a variety of resources via bridging social capital has been described in section 8.3. Key individuals who were employed by Parkinson's UK (Information and Support Workers, ISWs) acted as bridges and brokers, sharing, and transmitting information across and between the local groups. However, as carers became established in these organisations there was evidence that some also became a 'go to' person, a bridge or broker acting as conduits to signpost and share information shaping and extending the networks of others. This was achieved as they traversed the voluntary and community organisations increasing their interactions and their personal networks. Thus, as noted by Christakis and Fowler (2009) membership of these groups influenced the carers directly by their immediate contacts in the group and indirectly (through their contact with network bridges and brokers, including the ISWs) with members beyond their immediate group or range of contacts.

Across the informal and formal aspects of the network the carer's role as a co-ordinator of care became apparent. As the care trajectory progressed this role became more evident, and the carers became more adept at drawing on their resources of social, economic, and cultural health capital (Bourdieu and Wacquant 1992; Halpern, 2005; Collyer et al., 2010, 2015; Shim, 2010). As described in section 8.2.2, co-ordination

within the personal community involved intricate negotiations particularly with the family and at times with friends. The nature of these negotiations was based on past histories, shared biographies, and the relational dynamics of the carer with different alters in their personal community (Dannefer, 2003; Settersten & Gannon, 2005; Solimeo, 2009; Fine & Glendinning, 2005). In deciding that the time was right to call on support from her brother, Monica contemplated several intersecting factors as she began to make her arrangements. Utilising her medical knowledge and previous experience of PD she recognised her father's deteriorating condition and was conscious of the transition that was beginning to take place in his care needs, whilst also being cognisant of her brother's changing circumstances and his increased availability to provide care. Thus, the interdependencies and biographical relationships that formed their family dynamic was integral to her understanding of the possibilities of how this support might be accessed (Finch & Mason, 1993; Dannefer, 2003; Settersten & Gannon, 2005; Solimeo, 2009; Fine & Glendinning, 2005). Utilising and accessing her bonding social capital also allowed Monica to call on family and friends to assist her brother while she was away.

For those carers whose family member was becoming more debilitated by PD, network organisation and co-ordination with the formal sector could be complicated, and time consuming. In these cases, where the scenario was complex several factors appeared to juxtapose. Principally, multiple organisations/facilities straddling health and social care were involved, the systems or processes were unreliable and often there was an extensive and diverse range of health and social care professionals involved in the care-recipient's treatment and care (Fotaki, 2010; Collyer et al., 2017). Thus, often there was a 'gap' or barrier in the exchange and flows of information that hindered support and access to treatment. These 'gaps' have been recognised in health and social care practice that can consist of professional silos and a lack of connectivity between health and social care providers. Collaboration in healthcare is essential and the existence of cultural and geographical 'gaps' between professionals, departments, organisations and between the professional and the carer/care-recipient can be detrimental to patient care and efficiency (Brathwaite, 2010).

To facilitate transactions across differing professional groups and organisations, the carer became a network bridge or broker. The term boundary spanner could also be used since it was evident that Dawit was crossing the boundaries between his informal

and formal networks, between different professional groupings and health and social care agencies. When performing this role carers assisted in the transmission and flows of information between the care-recipient, professionals and health and social care organisations. Throughout the carers' accounts and especially for those dealing with a complex, rapidly changing situation this role was apparent. This 'work' often appeared to be associated with access and supply of medication and monitoring of the complex treatment regimes. The diary data captured this in 'real time' as Dawit, under time pressure, liaised and communicated across different pharmacists, the GP surgery and other health professionals while trying to acquire the drugs that were needed for his wife. The term 'go between' can also be used in this scenario as information is passed between two un-linked individuals thus facilitating the transmission of information, data, or resources. However, this can be time consuming and can result in overload for the individual in this role (Long et al., 2013).

The carer as a network bridge, broker or go-between and their role in co-ordinating the network offers a further dimension to previous discussions on the 'work' of chronic illness (Knowles et al., 2016; Vassilev et al., 2013; Corbin & Strauss; 1985). This has highlighted the difficulties and uncertainties they experience as they manage the network and emphasises the complexity of their role. Again, as they undertake this aspect of care work, the carer might be viewed as a resource or co-worker (Twigg, 1989; Twigg & Aitken, 1994). This has been a dominant view of carers, underpinned by an expectation and assumption that the family will be available to support the ageing population and those with long-term conditions such as PD (Finch, 1989; Finch & Mason, 1993; Twigg & Atkin, 1994; Ungerson, 1983, 1990, 2006; Yeandle et al., 2012). The discourse is evolving with policy and legislation focussing on carers as partners in care (NHS England, 2014b; DHSC, 2018a; 2018b) or co-clients with their own needs that should be addressed (Care Act, 2014). However, this work resonates with the findings of Aasbø et al., (2017) when carers become part of the field of health and social care practice. Principally, as carers negotiate across these fields there is a dissonance between the reality of their role when compared to the ideals stated in health and social care policy that promotes collaboration and partnership between carers and the formal sector.

8.6 The Networks of Family Carers of those with Parkinson's Disease: A Unique Context

This study sought to understand how the social networks of those caring for somebody with PD are shaped and how these social networks impact on the carers' role. Compared to the biomedical research on PD, there has been limited research to understand the lived experience of those with PD and their carers (Solimeo 2009; Stanley-Hermanns & Engbretson 2010; Gibson and Kierans, 2017). Furthermore, there is no research that explicitly offers an in-depth view of the networks of those who are the informal carers. Therefore, this work is distinct and unique in its focus. The findings demonstrate that the diagnosis and progression of PD impacts on the structure and evolution of the carers' networks of support in their role. Particularly the complex nature and unpredictability of the disease with its stigmatising features all meant that various types of bespoke support were valued and needed.

For many of the carers in this study, family and friends dominated the informal networks of support. Although the study was over a relatively short period there was a sense of dynamism and change in the carers' informal networks in relation to their friendship groups. As described in other work, significant alterations in social contact and activity were described as a direct result of the disease (Abendroth et al., 2012; Hounsgaard et al., 2011; McLaughlin, 2010). Following the diagnosis of PD, and as the disease progressed, led the carers and care recipients to seek new friendships through their activity in the Parkinson's UK groups. The stigmatising and embarrassing manifestations of the disease and reactions of friends (Caap-Ahlgren *et al* 2002; Schrag *et al* 2003; Soliimeo, 2009; Shildrick 1997; Nijhof, 1995) were discussed by some when reflecting on their changing friendship groups. Others in this study noted how the effects of PD began to limit the care-recipient's ability to socialise which subsequently impacted on them too (Hounsgaard et al., 2011; Solimeo, 2009; McLaughlin, 2010).

The role of Third Sector Organisations and their support of this group particularly via Parkinson's UK, was a constant theme throughout the participants data and is clearly articulated in the findings. The 'lifeline' that these organisations offered for this group was particular to their circumstances and the nature of PD as a condition and resonates with other studies (Abendroth, et al., 2014; Teahan, et al., 2020; West and Hogan, 2020). PD specific information and advice were important, and the nature of

Parkinson's UK and the associated groups offered experiential homophily (Perry & Pescosolido, 2015; Sutor & Keeton, 1997; Sutor et al., 1995; Thoits, 1986) which for this group was an important aspect. Carers (and the care-recipients) could feel accepted and valued and not experience the stigma, shame or discrimination that can be attached to PD (Caap-Ahlgren *et al* 2002; Schrag *et al* 2003; Soliimeo, 2009; Shildrick 1997; Nijhof, 1995). The emotional support that was available was significant and increasingly became an important part of membership. There was a sense of belonging and unity with other carers and those who had been diagnosed with PD. A strength of the disease-specific nature of the PD group was the bespoke nature of the support that it provided. Thus, those activities that enhanced cognitive and physical wellbeing were particularly needed for a condition that can be so debilitating in both respects. Also, for the carers, the development of PD-related knowledge and skills that could assist them in their role was viewed as invaluable.

The provision of PD focussed healthcare services was found to be disparate and as such the carers found navigation across this aspect of the network particularly difficult at times. Service provision was complex with varying models of care being provided according to geographical location and available resources. Where linking social capital was disrupted or absent due to the fragmentation of PD services or organisational and structural constraints, the carers had real difficulties in accessing and co-ordinating appropriate care. Read et al., (2019, p.1) in their examination of services from the patient perspective found that patients had to 'fit-in' to services and that these did not always accommodate their complex needs. The sense of the carer not being fully integrated as care progressed, with a lack of continuity and coordination, symptom mismanagement and care opportunities missed, also echoes the work of McLaughlin et al. (2011). This work has offered a unique view of PD services from the carer perspective that resonates with these findings. Furthermore, participants in this study highlighted that in this aspect of the network, information, advice, and signposting from health professionals was vital for them in their role as the carer. Although the NICE (2017) guidance is clear about the guidance and information that carers may need when patients start dopaminergic therapy in case of impulse disorders there is scope to identify the carer requirement for an identified point of contact in quality statement 1 (Adults with Parkinson's disease have a point of contact with specialist services.).

The role of the carer as a network bridge, broker and co-ordinator was particularly evident in this work in relation to medicines management which is known to be a difficult and complex task in PD. The availability and access to drugs for the condition was a constant concern for many of the carers. Particularly singled out was the important role of the pharmacist in supporting carers in their role of medicines management for the care-recipient. The complex nature and potential for side effects and drug interactions meant that a pharmacist's support and advice was vital.

The variability of the disease presentation and progression with its unpredictability, made co-ordination of support difficult and was compounded by the heterogeneity and disparate arrangements of the PD services. This further added to the 'work' of caring (Knowles et al., 2016; Vassilev et al., 2013; Corbin & Strauss, 1985) as they navigated and negotiated care across the network. Although the Parkinson's UK (2019) audit has highlighted issues in terms of specialised multidisciplinary working, communication and information sharing and medicines management, these do not completely reflect the issues that carers raised in this work since the audit does not have a 'carer only' perspective in the findings presented.

8.7 Evaluating the Methodology

Utilising a case methodology (Stake, 1995; Yin, 2009) with social network approaches has offered a valuable means of collecting data on this group of carers. The development of data collection tools that were underpinned by Cantor's (1979, 1991) Social Care Model and the Convoy Model of Care (Antonucci, 1985; Antonucci et al., 2009; Kahn & Antonucci, 1980) offered a means of clearly encompassing all the components of the informal and formal networks. This also helped to delineate the place of the TSOs, and especially the VCOs that the carer participated in. Sequential collection of the network, diary and interview data gave a comprehensive data set for each carer. The diary-interview design and carer examination of the sociograms aided a reflexive approach (Giddens, 1994; Rowson et al., 2010) that helped to uncover the nuances and various roles and significance of members in their network (Campbell et al., 2019; Ryan et al., 2014). In alignment with the interpretive, social constructivist ethos, the data was therefore co-produced with further development of the data during the interview (Denzin and Lincoln, 2013). The triangulation of the findings across the different methods, and the complementarity of each approach enabled a

comprehensive and detailed picture of the carers' networks to be uncovered (Hollstein, 2011). Framework analysis dovetailed with the case study methodology in allowing individual cases to be analysed in tandem with a comparative analysis across the cases.

8.8 Limitations of the Study

This was a small study set in a particular geographical region and with a focus on those caring for a relative with PD. Thus, the findings may not be generalisable. However, this work offers a detailed perspective of these carers' lives and their networks of support that should resonate with others caring for ageing relatives. The carers who participated were self-selecting, and recruitment via Parkinson's UK meant that all were involved in this organisation at some level. Thus, the findings will be reflective of those who were active in, and aligned to, the work and ethos of this organisation. It is recognised that there are many hidden carers (Cavaye, 2006; Barnes, 2012) who are unknown to health and social care providers and may not identify themselves in this role (Carduff et al., 2014). These people are not included in this work and therefore there is a gap in understanding of the shape and form that their networks may take and how they may access support as they undertake their role. The data collection was undertaken as the Care Act (2014) was being enacted and therefore will not fully reflect the changes that have occurred, particularly in social care, since that period. Thus, although a small number of carers in this study had received carer assessments (prior to the Act), the statutory requirement and processes for this assessment were not in place.

These findings relate to the 2013-2015 period, prior to the COVID-19 pandemic. Therefore, the work does not account for the subsequent impact of COVID-19 on the increase in those providing informal care, the outcome of the pandemic and how care was provided. The effects of the pandemic on the mechanisms of support for carers (and care-recipients) and the impact on their social networks have been significant (Carers UK, 2021). Extrapolating from the context of this study and on consideration of the findings presented, the loss of social contact with the major disruption to the networks of support at all levels would certainly have been to the detriment of carers and their care recipients.

8.9 Contribution to the Existing Body of Knowledge

As its contribution to knowledge, the study offered several key insights into the informal and formal networks of support of family carers of those with PD. There is currently minimal evidence on this group of carers in relation to their networks of support. The detail uncovered in the structure of the networks and their utility in the caring role clearly reflects the changing demographics of the UK and shifting societal norms. This offers health and social work professionals an in-depth understanding of the evolving nature of informal support and the complexities of the formal care network in the 21st Century. The intermediary role of the TSOs in their support of this group has not been previously examined in the UK. This study has clearly illuminated the valuable support that is accessed from TSOs, that is not available from the formal sectors, and yet acts synergistically with health and social care delivery. The carer as a network bridge, broker and co-ordinator is a novel view of the carers' role which places them as co-workers in the fields of health and social care. This further underscores the need for PD care services to be fully integrated to improve access, navigation and the quality of care provided (Parkinson's, UK 2019; NHS England, 2019c). Furthermore, this also adds to the body of knowledge about the various facets of 'illness work' that carers undertake (Knowles et al., 2016; Vassilev et al., 2013; Corbin and Strauss; 1985). The case study methodology, with the social network data, diaries and interviews offered a complementary approach with each case forming a holistic unit of analysis. With carer participation through visualisation of the network data, these methods certainly gave a very comprehensive and detailed view of the carers' networks (Hollstein, 2011). This approach could be applied in a range of settings and with different carers, service user groups or professionals. Dissemination strategies have been on-going, and will now continue, to facilitate the study's contribution to the existing body of knowledge.

8.10 Implications for Education, Practice and Research

Carers are providing substantial support to an ageing population. However, although government policies and Acts have focussed on carers rights including the Recognition and Services Act (1995), the Carers Equal Opportunities Act (2004), and

most recently the Care Act (2014), the positive benefits of this legislation have not substantially improved the support or provision for the carers in this study. The Care Act (2014) was only enacted during the period of data collection and therefore it was difficult to judge if there was any impact on carer support for these participants. However, early findings on the impact on carer assessment since the Act came into force are disappointing with estimates that only six per cent of carers receive support from adult social services (NAO, 2018b) and that in 2019, just 27% of carers had been assessed or reassessed in line with the Care Act (Carers UK, 2019). For carers of those with PD it is already known that only a small proportion access formal care services to assist them in caring at home despite the care-recipients having significant motor and non- motor symptoms (Hand et al., 2018). However, it is known that the care burden can become unmanageable for these carers with a risk that institutionalisation will be the only option (Abendroth et al., 2012). NICE (2020) in acknowledging the difficulties that carers face has also released guidance for best practice aimed at improving outcomes for adult carers. To address the difficulties, and for professionals to fulfil the duties of the Care Act (2014), they must be able to recognise those providing care, assess their needs and identify and signpost the resources needed to enable the carer to continue in their role. Understanding the intricacies of the carers' networks, including the resilience and capacity of these networks to provide care for somebody with PD (or other long-term condition), will facilitate this. The problems and difficulties relating to disparate services for those with PD have been acknowledged (Parkinson's, UK 2019; NHS England, 2019c) and were apparent in the findings of this study, impacting on the quality of care and adding to carer burden. Improvements are needed to integrate care and to ensure wider access to specialist services. The increasing need for respite as the care demands increase was a particular element of support that was discussed by several carers in this study. This does not necessarily have to be long periods of respite but maybe smaller periods of time that could be taken on a regular basis. The findings of this work can therefore inform the learning and practice of both practitioners and students who are training in professions connected to health and social care. The findings also suggest further avenues for research.

8.10.1 Recommendations for Health and Social Care Professional Education

1. For carers to receive greater recognition and support, education for all healthcare professionals needs to convey the complexity of the carers' role and the work involved. This will develop the appropriate understanding, knowledge, skills, and attributes that will assist in identifying and assessing carers and their needs. This will enable greater collaboration and effective partnership working.
2. Exploring the socio-political and economic dimensions of care and demographic change will allow students to recognise the impact on 'the family' and those informal and formal networks of support.
3. To ensure carers are identified, explore carer identity to recognise when carers may be hidden or excluded from health and social care arenas and TSOs.
4. The individual needs of those caring for somebody with PD alongside other groups of carers should be examined with an emphasis on parity of esteem with the care-recipient's needs.
5. The valuable role that TSOs, (including VCOs) provide in terms of support and their synergistic interaction with formal services needs to be clearly addressed in training so that these services can be clearly signposted.

8.10.2 Recommendations for Practice

The first two recommendations are aligned with the NICE (2020) guidance.

1. Health and social care providers should ensure that carer expertise is recognised allowing them to act as expert partners in care. Trust, respect, and mutuality should be developed with carers through partnership working and acknowledgement of the knowledge and skills they possess. about the person they care for. Local policies and processes should underpin this work.
2. Health and social care practitioners should recognise the work of caring and ensure that carers are valued as a member of the care team. They should involve the carer (if both they and the care-recipient wish) in all aspects of care delivery.
3. Carer assessments should gather detail on the carers' networks to assess the capacity of the network and to identify resources that may facilitate greater support in the network

4. Appropriate information, support and signposting should be provided for carers in line with the Care Act (2014). This should cover details on access to support services including carer groups and disease-focussed forums.

8.10.3 Recommendations for Future Research

1. It is suggested that utilising a network approach, those involved in planning or commissioning services undertake a detailed scoping exercise on the range and provision of services offered by TSOs, (including VCOs) that are available to carers.
2. Research to identify the impact of the NHS England (2019c) Toolkit for Progressive Neurological Conditions on service organisation and delivery.
3. A high quality comprehensive systematic review or research to identify the impact of the Care Act (2014) on carer assessment and the delivery of services targeted to the carer.
4. A detailed scoping exercise on the availability, eligibility criteria and range of carer breaks and respite care.
5. Research to assess the outcomes and benefits of the Carer Champion/Navigator roles.

8.11 Summary

By using Bourdieu's concepts of habitus, field, and capital (Bourdieu, 1986; Bourdieu & Wacquant, 1992; Bourdieu, 2007) this chapter has explored how carers access resources across the different 'fields' of informal and formal care provision. It has demonstrated the complexities of navigation and negotiation across the informal and formal care provision to access the resources they need. The carer as a network, bridge, broker, and co-ordinator is a novel view of their role and captures their orchestration of the network. This adds to the complexity and 'work' of caring (Knowles et al., 2016; Vassilev et al., 2013; Corbin and Strauss; 1985). Within the carers' personal community and at the interface with formal care provision and TSOs, the carers are part of complex transactional processes that are shaped by the habitus of each field and mediated by social, cultural, and economic capital. The role of bonding, bridging, and linking social capital were identified as important to the carers' role and as a means of accessing care and support. However other personal resources,

principally cultural health capital and finances were also key. A heterogenous picture of the carers' networks and the support provided to the carers in their role is presented across the micro and meso fields of care. The impact of demographic change and shifting societal norms alongside Government policy on health and social care are illustrated in the carers' personal community and formal care networks.

The role of TSOs as intermediaries between the informal and formal fields is clearly articulated with the support offered acting as a *lifeline*. Furthermore, within this field accessing bridging social capital aided the development of the carers' cultural health capital which assisted their negotiations with formal providers of care offering a synergy across these two fields. Within the field of health and social care the range and quality of services in relation to PD was variable and access was disparate. Navigation across this field was difficult at times, with structural and organisational barriers limiting access to care. Those who became adept at accessing formal care services drew on their personal resources (be it economic, social, or cultural health capital). Care was shaped by their own personal habitus in terms of their expectations of healthcare, their personal cultural and health capital and their desire for autonomy and control in managing their health and their unique care situation. Structural and organisational deficits and conflicts between the providers and carers limited the development of linking social capital thus hindering navigation and access. The importance of the relational dynamics of the network, through transactional processes across the network could act as a facilitator or barrier to support. This is an important consideration since social capital might be viewed as merely an exchange or acceptance of a resource (be it affective, instrumental, or social support). However, it cannot be extricated from social relationships.

The case study approach and the methods used were a valuable approach that has potential for application in other areas. This work offers new insights into the carers networks and further underlines the complexities of the role. This work will assist health and social care practitioners to identify and assess carers' needs in the context of their personal community, therefore identifying the most appropriate resources for them as required by the Care Act (2014). Furthermore, this work has highlighted deficiencies in the formal network and considers where future work should be targeted to address these deficiencies

Chapter 9 Conclusion

This case study research is the only work that has sought to uncover the social networks of carers of family members with PD and their function in the caring role. The impact of demographic and societal change, alongside government policy on health and social care, are illustrated in the carers' personal community and formal care networks. Using a Bourdieusian lens and social network approaches, the work has identified the carer's role as a network bridge, broker, and co-ordinator as they navigate and negotiate across the informal and formal fields of care. Support is accessed through bonding, bridging, and linking social capital whilst also drawing on other personal resources of economic and cultural health capital. If care policies and practice continue to be underpinned by an expectation and assumption that the family will be available to support the ageing population and those with long-term conditions such as PD, the resilience and capacity of these networks needs to be assessed and understood if carers are to be appropriately supported. Furthermore, there is a dissonance in the rhetoric of policy and the requirements of statute when compared to the realities of practice. Although the prevailing discourse is one of partnership with the carer as a co-client and expert in care, in practice the carer becomes a co-worker and 'go-between' as they traverse the formal networks of care, bridging the gaps caused by the deficits in provision. This study confirmed that partnership care between carers, organisations, and health and social care practitioners, requires carer recognition as an expert in care, and the development of relationships built on trust, respect, and mutuality. This further underlines the importance of the moral and ethical dimensions of care delivery, which should underpin the education of health and social care professionals, and through policies and processes, shape the culture of practice. Understanding the structure and function of carers' informal networks can support the provisions of the Care Act (2014) by assisting health and social care practitioners in identifying carers, assessing their needs in the context of their personal community, and identifying the most appropriate resources for them. Finally, this study has demonstrated the impact on carers where there are 'gaps' and deficits in the formal networks and highlights where future work could be targeted to address these deficiencies.

References

- Aarsland, D., Larsen, J. P., Karlsen, K., Lim, N. G., & Tandberg, E. (1999). Mental symptoms in Parkinson's disease are important contributors to caregiver distress. *Int J Geriatr Psychiatry*, *14*(10), 866-874.
- Abel, T., & Frohlich, K. L. (2012). Capitals and capabilities: Linking structure and agency to reduce health inequalities. *Social science & medicine*, *74*(2), 236-244.
- Abendroth, M., Greenblum, C. A., & Gray, J. A. (2014). The Value of Peer-Led Support Groups Among Caregivers of Persons With Parkinson's Disease. *Holistic Nursing Practice*, *28*(1), 48-54.
- Abendroth, M., Lutz, B. J., & Young, M. (2012). Family caregivers' decision process to institutionalize persons with Parkinson's disease: A grounded theory study. *International journal of nursing studies*, *49*, 445-454.
- ADASS. (2018). Autumn Budget 2018 – Representation by The Association Of Directors Of Adult Social Services Retrieved from <https://www.adass.org.uk/autumn-budget-2018-representation-by-adass>
- Alaszewski, A. (2006). *Using Diaries for Social Research*. London: Sage.
- Allan, G. (2008). Flexibility, friendship, and family. *Personal Relationships*, *15*(1), 1-16.
- Allen, D. (2000). Negotiating the role of expert carers on an adult hospital ward. *Sociology of Health & Illness*, *22*(2), 149-171.
- Amaro, L. M. (2017). Dyadic effects of gratitude on burden, conflict, and contribution in the family caregiver and sibling relationship. *Journal of Applied Communication Research*, *45*(1), 61-78.
- Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: does it matter?. *Journal of health and social behavior*, 1-10.
- Anderson, L., Lofland, J., Lofland, L., & Snow, D. (2006). Analyzing social setting: a guide to qualitative observation and analysis. In: Belmont, CA: Wadsworth Publishing Co.
- Aneshensel, C. S. (1995). *Profiles in caregiving : the unexpected career*. San Diego ; London: Academic Press.
- Angus, J., Kontos, P., Dyck, I., McKeever, P. and Poland, B. (2005), The personal significance of home: habitus and the experience of receiving long-term home care. *Sociology of Health & Illness*, *27*: 161-187.
- Antonucci, A. C. (1985). *Personal characteristics, social networks, and social behavior* (R. Binstock & E. Shanas Eds.). New York: Van Nostrand Reinhold, Academic Press.
- Antonucci, T. C., Birditt, K. S., & Akiyama, H. (2009). Convoys of social relations: An interdisciplinary approach. *Handbook of theories of aging* (pp. 247–260). Springer Publishing Company
- Appleby, J., Harrison, A., Devlin, N., Richardson, H., & Stanley, E. (2003). *What is the real cost of more patient choice?* [London]: [King' Fund].
- Arksey, H., & Glendinning, C. (2007). Choice in the context of informal care-giving. *Health & Social Care in the Community*, *15*(2), 165-175.
- Aasbø, G., Solbrække, K. N., Kristvik, E., & Werner, A. (2016). Between disruption and continuity: challenges in maintaining the 'biographical we' when caring for a partner with a severe, chronic illness. *Sociology of Health & Illness*, *38*(5), 782-796.
- Aasbø, G., Rugkåsa, J., Solbrække, K. N., & Werner, A. (2017). Negotiating the care-giving role: family members' experience during critical exacerbation of COPD in Norway. *Health & social care in the community*, *25*(2), 612-620.
- Atkinson, R., & Flint, J. (2001). Accessing Hidden and Hard-to-Reach Populations: Snowball Research Strategies *Social Research Update*(33).
- Baggott, R., & Jones, K. (2014). The voluntary sector and health policy: The role of national level health consumer and patients' organisations in the UK. *Social Science & Medicine*, *123*, 202-209.

- Balducci, C., Mnich, E., McKee, K. J., Lamura, G., Beckmann, A., Krevers, B., . . . Oberg, B. (2008). Negative impact and positive value in caregiving: validation of the COPE index in a six-country sample of carers. *Gerontologist, 48*(3), 276-286.
- Barbour, R. S. a. (2014). *Introducing qualitative research : a student's guide* (Second edition. ed.).
- Barnes, M. (2012). *Care in everyday life an ethic of care in practice*. Bristol: Policy Press.
- Barron, D. N., & West, E. (2017). The quasi-market for adult residential care in the UK: Do for-profit, not-for-profit or public sector residential care and nursing homes provide better quality care? *Soc Sci Med, 179*, 137-146.
- Bartlett, R. (2012). Modifying the Diary Interview Method to Research the Lives of People With Dementia. *Qualitative Health Research, 22*(12), 1717-1726.
- Baum, F. E. (1999). Social Capital: Is It Good for Your Health? Issues for a Public Health Agenda. *Journal of Epidemiology and Community Health (1979-), 53*(4), 195-196.
- Baxter, K., & Glendinning, C. (2015). *People who fund their own social care (SSCR Scoping Review)*. Retrieved from York:
- Bazeley, P. (2004). Issues in Mixing Qualitative and Quantitative Approaches to Research. In R. Buber, J. Gadner, & L. Richards (Eds.), *Applying qualitative methods to marketing management research*. Basingstoke ; New York: Palgrave Macmillan.
- Bearman, P., & Parigi, P. (2004). Cloning Headless Frogs and Other Important Matters: Conversation Topics and Network Structure. *Social Forces, 83*(2), 535-557.
- Beesley, L. (2006). *Informal Care in England*. London: King's Fund.
- Bell, D., & Rutherford, A. (2013). Individual and Geographic Factors in the Formation of Care Networks in the UK. *Population, Space and Place, 19*(6), 727-737.
- Bengtson, V., & Allen, K. (1993). The Life Course Perspective Applied to Families Over Time. In (pp. 469-504).
- Bengtson, V., & Roberts, E. (1991). Intergenerational Solidarity in Aging Families: An Example of Formal Theory Construction. *Journal of Marriage and Family, 53*(4), 856-870.
- Bengtson V.L., & K.R., Allen. (2009). The Life Course Perspective Applied to Families Over Time. In Boss P., Doherty W.J., LaRossa R., Schumm W.R., & S. S.K. (Eds.), *Sourcebook of Family Theories and Methods*. . Boston, MA.: Springer.
- Bengtson, V. L. (2001). Beyond the Nuclear Family: The Increasing Importance of Multigenerational Bonds. *Journal of Marriage and Family, 63*(1), 1-16.
- Berrington, A. (2017). Childlessness in the UK. In *Childlessness in Europe: Contexts, causes, and consequences* (pp. 57-76). Springer, Cham.
- Blackburn, C., Read, J., & Hughes, N. (2005). Carers and the digital divide: factors affecting Internet use among carers in the UK. *Health & Social Care in the Community, 13*(3), 201-210.
- Boneham, M. A., & Sixsmith, J. A. (2006). The voices of older women in a disadvantaged community: Issues of health and social capital. *Social Science & Medicine, 62*(2), 269-279.
- Borgatti, S., & Lopez-Kidwell, V. (2011). Network Theory. In P. J. Carrington & J. Scott (Eds.), *The SAGE handbook of social network analysis*. London: SAGE.
- Borgatti, S., Mehra, A., Brass, D., & Labianca, G. (2009). Network Analysis in the Social Sciences. *Science, 323*(5916), 892-895.
- Bott, E. (1955). Urban families: Conjugal roles and social networks. *Human relations, 8*(4), 345-384.
- Bourdieu, P. (1986). The forms of social capital. In J. G. Richardson (Ed.), *Handbook of theory and research for the sociology of education*. Westport, CT: Greenwood Press.
- Bourdieu, P. (2007). *Outline of a Theory of Practice*: Duke University Press.
- Bourdieu, P., & Wacquant, L. (1992). *Invitation to Reflexive Sociology*: London: Polity Press.
- Boutin-Foster, C., & Charlson, M. E. (2002). Getting to the heart of social support: A qualitative study on the mechanisms of action of social support among patients with coronary artery disease. *Journal of Clinical Epidemiology, 55*(6), 629.
- Bowes, A., Dawson, A., & Ashworth, R. (2020). Time for care: exploring time use by carers of older people. *Ageing and Society, 40*(8), 1735-1758.

- Bowlby, S. (2011). Friendship, co-presence and care: neglected spaces. *Social & Cultural Geography*, 12(6), 605-622.
- Bowling, A. (1994). Social networks and social support among older people and implications for emotional well-being and psychiatric morbidity. *International Review of Psychiatry*, 6(1), 41-58.
- Bowling, A., Farquhar, M., & Browne, P. (1991). Life satisfaction and associations with social network and support variables in three samples of elderly people. *International Journal of Geriatric Psychiatry*, 6(8), 549-566.
- Braithwaite, J. (2010). Between-group behaviour in health care: Gaps, edges, boundaries, disconnections, weak ties, spaces and holes. A systematic review. *BMC Health Services Research*, 10, 330. doi:10.1186/1472-6963-10-330
- Bramley, N., Eatough, V. (2005) The experience of living with Parkinson's Disease: An interpretive phenomenological analysis case study *Psychology and Health* 20: 2 223-235
- Braun, V., & Clarke, V. (2013). *Successful qualitative research : a practical guide for beginners*. London: SAGE.
- Brimblecombe, N., Fernandez, J.-L., Knapp, M., Rehill, A., & Wittenberg, R. (2018). Review of the international evidence on support for unpaid carers. *Journal of Long-term Care*, , 25–40.
- Brody, E. M. (1981). "Women in the middle" and family help to older people. *Gerontologist*, 21(5), 471-480.
- Broese van Groenou, M., Jacobs, M., Zwart-Olde, I., & Deeg, D. J. (2016). Mixed care networks of community-dwelling older adults with physical health impairments in the Netherlands. *Health Soc Care Community*, 24(1), 95-104.
- Broese van Groenou, M. I., & De Boer, A. (2016). Providing informal care in a changing society. *European Journal of Ageing*, 13(3), 271-279.
- Brossard, B., & Carpentier, N. (2017). To what extent does diagnosis matter? Dementia diagnosis, trouble interpretation and caregiving network dynamics. *Sociology of Health & Illness*, 39(4), 566-580.
- Bryman, A., and Teevan, J. T. (2005) *Social Research Methods* (Canadian edn). Ontario: Oxford University Press.
- Buckner, L., & Yeandle, S. (2011). *Valuing Carers 2011. Calculating the value of carers' support*. Retrieved from London:
- Burt, R. S. (1984). Network items and the general social survey. *Social Networks*, 6(4), 293-339.
- Burt, R. S. (1985). General social survey network items. *Connections*, 8, 119-123.
- Burt, R. S. (1992). *Structural holes : the social structure of competition*. Cambridge, MA ; London: Harvard University Press.
- Burt, R. S. (1997). A note on social capital and network content. *Social Networks*, 19(4), 355-373.
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of health & illness*, 4(2), 167-182.
- Bury, M. R. (1986). Social constructionism and the development of medical sociology. *Sociology of health & illness*, 8(2), 137-169.
- Caap-Ahlgren, M., Lannerheim, L., & Dehlin, O. (2002). Older Swedish women's experiences of living with symptoms related to Parkinson's disease. *Journal of advanced nursing*, 39(1), 87-95.
- Cabinet Office. (2010). *Building the big society*. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/78979/building-big-society_0.pdf
- Campbell, C., & McLean, C. (2002). Ethnic identities, social capital and health inequalities: factors shaping African-Caribbean participation in local community networks in the UK. *Social Science & Medicine*, 55(4), 643-657.
- Campbell, S., Clark, A., Keady, J., Kullberg, A., Manji, K., Rummery, K., & Ward, R. (2019). Participatory social network map making with family carers of people living with dementia. *Methodological Innovations*, 12(1),

- Cantor, M. H. (1979). Neighbors and friends: An overlooked resource in the informal support system. *Research on aging*, 1(4), 434-463.
- Cantor, M. H. (1991). Family and Community: Changing Roles in an Aging Society. *The Gerontologist*, 31(3), 337-346.
- Carduff, E., Finucane, A., Kendall, M. *et al.* Understanding the barriers to identifying carers of people with advanced illness in primary care: triangulating three data sources. *BMC Fam Pract* 15,48 (2014). <https://doi.org/10.1186/1471-2296-15-48>
- Care Act (2014), Ch 23 (TSO)
- Care Quality Commission. (2016). *Building bridges, breaking barriers*, . Retrieved from London: https://www.cqc.org.uk/sites/default/files/20160712b_buildingbridges_report.pdf
- Carers (Recognition and Services) Act, (1995). HMSO
- Carers and Disabled Children's Act, (2000). HMSO
- Carers Equal Opportunity Act, (2004). HMSO
- Carers UK. (2004). *In Poor Health: The Impact of Caring on Health*. Retrieved from London:
- Carers UK. (2010). *Tipping Point for Care: Time for a New Social contract* [PDF]. Retrieved from <http://www.carersuk.org/professionals/resources/research-library/item/495-tipping-point-for-care-time-for-a-new-social-contract>
- Carers UK. (2015). Valuing Carers : The rising value of carers' support. Retrieved from https://www.sheffield.ac.uk/polopoly_fs/1.546409!/file/Valuing-Carers-2015.pdf
- Carers UK. (2016a). Pressure Points: carers and the NHS. Retrieved from <https://www.carersuk.org/for-professionals/policy/policy-library/pressure-points-carers-and-the-nhs>
- Carers UK. (2016b). State of Caring. Retrieved from file:///C:/Users/hthqjs1/Downloads/uk4074-state-of-caring-2016-report%20(1).pdf
- Carers UK. (2019). State of Caring: A snapshot of unpaid care in the UK. Retrieved from http://www.carersuk.org/images/News_campaigns/CUK_State_of_Caring_2019_Report.pdf
- Carers UK. (2021). State of Caring: A snapshot of unpaid care in the UK. Retrieved from [file:///C:/Users/hthqjs1/Downloads/cukstateofcaring2021reportdigital%20\(1\).pdf](file:///C:/Users/hthqjs1/Downloads/cukstateofcaring2021reportdigital%20(1).pdf)
- Carpentier, N., Bernard, P., Grenier, A., & Guberman, N. (2010). Using the life course perspective to study the entry into the illness trajectory: the perspective of caregivers of people with Alzheimer's disease. *Social science & medicine* (1982), 70(10), 1501-1508.
- Carpentier, N., & Ducharme, F. (2003). Care-giver network transformations: the need for an integrated perspective. *Ageing and Society*, 23(4), 507-525.
- Carpentier, N., & Ducharme, F. (2005). Support network transformations in the first stages of the caregiver's career. *Qualitative Health Research*, 15(3), 289-311.
- Carpentier, N., Ducharme, F., Kergoat, M.-J., & Bergman, H. (2008). Social Representations of Barriers to Care Early in the Careers of Caregivers of Persons With Alzheimer's Disease. *Research on Aging*, 30(3), 334-357.
- Carpentier, N., & Grenier, A. (2012). Successful Linkage Between Formal and Informal Care Systems: The Mobilization of Outside Help by Caregivers of Persons With Alzheimer's Disease. *Qualitative Health Research*, 22(10), 1330-1344.
- Carpentier, N., Pomey, M.-P., Contreras, R., & Olazabal, I. (2008). Social care interface in early-stage dementia: practitioners' perspectives on the links between formal and informal networks. *Journal of aging and health*, 20(6), 710-738.
- Carter, T., & Beresford, P. (2000). *Age and change: models of involvement for older people*: Joseph Rowntree Foundation.
- Cattell, V. (2001). Poor people, poor places, and poor health: the mediating role of social networks and social capital. *Social Science & Medicine*, 52(10), 1501-1516.
- Cavaye, J. (2006). *Hidden carers*. Edinburgh: Dunedin Academic.

- Charlesworth, G., Burnell, K., Beecham, J., Hoare, Z., Hoe, J., Wenborn, J., . . . Orrell, M. (2011). Peer support for family carers of people with dementia, alone or in combination with group reminiscence in a factorial design: study protocol for a randomised controlled trial. *Trials*, *12*, 205.
- Charlesworth, G., Tzimoula, X., Higgs, P., & Poland, F. (2007). Social networks, befriending and support for family carers of people with dementia. *Quality in Ageing and Older Adults*, *8*(2), 37-44.
- Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of health & illness*, *5*(2), 168-195.
- Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. Rutgers University Press.
- Charmaz, K. (1995). The body, identity, and self: Adapting to impairment. *Sociological quarterly*, *36*(4), 657-680.
- Charmaz, K. (2006). *Constructing grounded theory*. London: SAGE Publications Ltd.
- Christakis, N. A., & Fowler, J. H. (2009). *Connected: The surprising power of our social networks and how they shape our lives*: Little, Brown Spark.
- Cohen, S., & Wills, T. (1985). Stress, social support and the buffering hypothesis. *Psychological Bulletin*, *98*, 310-356.
- Coleman, J. S. (1988). Social Capital in the Creation of Human Capital. *American Journal of Sociology*, *94*, S95-S120.
- Coleman, M., Ganong, L. H., & Rothrauff, T. C. (2006). Racial and ethnic similarities and differences in beliefs about intergenerational assistance to older adults after divorce and remarriage. *Family Relations*, *55*(5), 576-587.
- Collyer, F. M., Willis, K. F., Franklin, M., Harley, K., & Short, S. D. (2015). Healthcare choice: Bourdieu's capital, habitus and field. *Current Sociology*, *63*(5), 685-699.
- Collyer, F. M., Willis, K. F., & Lewis, S. (2017). Gatekeepers in the healthcare sector: Knowledge and Bourdieu's concept of field. *Soc Sci Med*, *186*, 96-103.
- Colombo, F., Llena-Nozal, A., Mercier, J., & Tjadens, F. (2011). *Help Wanted? Providing and Paying for LongTerm Care*. Paris: OECD
- Commission of the European Communities. (2005). *Confronting demographic changes: A new solidarity between the generations*. Brussels: European Commission
- Connidis, I., & Barnett, A. (2019). *Family ties & aging* (3rd ed.). Los Angeles. London: Sage.
- Connidis, I., & McMullin, J. (2002). Sociological Ambivalence and Family Ties: A Critical Perspective. *Journal of Marriage and Family*, *64*(3), 558-567.
- Conrath, D. W., Higgins, C. A., & McClean, R. J. (1983). A comparison of the reliability of questionnaire versus diary data. *Social Networks*, *5*(3), 315-322.
- Corbin, J., & Strauss, A. (1985). Managing chronic illness at home: three lines of work. *Qualitative sociology*, *8*(3), 224-247.
- Corden, A., & Hirst, M. (2011). Partner care at the end-of-life: identity, language and characteristics. *Ageing & Society*, *31*(2), 217-242.
- Corti, L. (1993). Using diaries in social research. *Social Research Update*, (2).
- Coyne, I. T. (1997). Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? *Journal of Advanced Nursing*, *26*(3), 623-630.
- Creswell, J. W. (2009). *Research Design Qualitative, Quantitative, and Mixed Methods Approaches* (Third Edition ed.). London: Sage.
- Crinson, I. (2008). The Health Professions. In G. Scambler (Ed.), *Sociology as applied to medicine* (6th ed., pp. 252-264). [Edinburgh]: Saunders Elsevier.
- Critical Appraisal Skills Programme. (2018). CASP Checklists.
- Crossley, M. L., & Crossley, N. (2001). Patient'voices, social movements and the habitus; how psychiatric survivors 'speak out. *Social Science & Medicine*, *52*(10), 1477-1489.
- Crotty, M. (2003) *The Foundations of Social Research: Meaning and Perspectives in the Research Process*. Thousand Oaks, CA: Sage.

- Curry, N., Mundle, C., Sheil, F., & Weeks, L. (2011). *The voluntary and community sector in health: Implications of the proposed NHS reforms*: King's Fund.
- Daly, M., & Lewis, J. (2000). The concept of social care and the analysis of contemporary welfare states. *The British journal of sociology*, 51(2), 281-298.
- Daly, M. (2002). Care as a good for social policy. *Journal of Social Policy*, 31(2), 251-270.
- Dam, A. E. H., Boots, L. M. M., van Boxtel, M. P. J., Verhey, F. R. J., & de Vugt, M. E. (2018). A mismatch between supply and demand of social support in dementia care: a qualitative study on the perspectives of spousal caregivers and their social network members. *International psychogeriatrics*, 30(6), 881-892.
- Dannefer, D. (2003). Cumulative Advantage/Disadvantage and the Life Course: Cross-Fertilizing Age and Social Science Theory. *The Journals of Gerontology: Series B*, 58(6), S327-S337.
- Data Protection Act, (1998)*. HMSO
- Data Protection Act, (2018)*. TSO
- Dawson, A., Bowes, A., Kelly, F., Velzke, K., & Ward, R. (2015). Evidence of what works to support and sustain care at home for people with dementia: a literature review with a systematic approach. *BMC Geriatrics*, 15(1), 1-17.
- Denzin, N. K., and Lincoln, Y. S. (2013) The discipline and practice of qualitative research. In N. K. Denzin and Y. S. Lincoln (eds), *The Landscape of Qualitative Research*, 1–41. Thousand Oaks, CA: Sage.
- Department of Health. (2001). *Valuing People: A New Strategy for Learning Disability for the 21st Century*. London: The Stationery Office.
- Department of Health (2006). *Our Health, Our Care, Our Say : A New Direction for Community Services: Executive Summary*. London: The Stationery Office
- Department of Health. (2007). *Putting people first*. London: Department of Health.
- Department of Health. (2009). *Valuing People Now: A New Three-year Strategy for People with Learning Disabilities*. London: Central Office of Information
- Department of Health. (2010a). *Recognised, valued and supported: Next steps for the carers strategy*. [PDF]. Retrieved from www.dh.gov.uk/publications
- Department of Health. (2010b). *Practical Approaches to Co-production*. London: Department of Health.
- Department of Health. (2014). Care and Support Statutory Guidance Issued under the Care Act 2014. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/506202/23902777_Care_Act_Book.pdf
- Department of Health and Social Care. (2015). *The NHS Constitution*. Retrieved from <https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england>
- Department of Health and Social Care. (2018a). *Carers Action Plan 2018-20*. London Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/713781/carers-action-plan-2018-2020.pdf
- Department of Health and Social Care. (2018b). *The Government's revised mandate to NHS England for 2018-19* London Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/803111/revised-mandate-to-nhs-england-2018-to-2019.pdf
- Department of Work and Pensions. (2020). Family Resources Survey 2018-2019. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/874507/family-resources-survey-2018-19.pdf
- Dickinson, H., & Glasby, J. (2010). The personalisation agenda: implications for the third sector.

- Dolan, A. (2007). 'That's just the cesspool where they dump all the trash': exploring working class men's perceptions and experiences of social capital and health. *Health*, 11(4), 475-495.
- Dominguez, S., & Watkins, C. (2003). Creating Networks for Survival and Mobility: Social Capital Among African-American and Latin-American Low-Income Mothers. *Social Problems*, 50(1), 111-135.
- Donabedian, A. (1988), 'The quality of care: how can it be assessed?', *Journal of the American Medical Association*, 260: 12, 1743-8
- Dow, B., & McDonald, J. (2007). The invisible contract: shifting care from the hospital to the home. *Australian health review : a publication of the Australian Hospital Association*, 31(2), 193-202.
- Draucker, C. B., Martsof, D. S., Ross, R., & Rusk, T. B. (2007). Theoretical Sampling and Category Development in Grounded Theory. *Qualitative Health Research*, 17(8), 1137-1148.
- Durkheim, E., & Halls, W. D. (1984). *The division of labor in society*. New York: Free Press.
- Dykstra, P. A., & Hagestad, G. O. (2007). Roads less taken: Developing a nuanced view of older adults without children. *Journal of family issues*, 28(10), 1275-1310.
- Easter, M. M., Henderson, G. E., Davis, A. M., Churchill, L. R., & King, N. M. P. (2006). The many meanings of care in clinical research. *Sociology of Health and Illness*, 28(6), 695-712.
- Edwards, B., & Foley, M. W. (1998). Social capital and civil society beyond Putnam. *American Behavioral Scientist*, 42(1), 124-140.
- Egdell, V. (2012a). Development of Support Networks in Informal Dementia Care: Guided, Organic, and Chance Routes through Support. *Canadian Journal on Aging*, 31(4), 445-455.
- Egdell, V. (2012b). Who cares? Managing obligation and responsibility across the changing landscapes of informal dementia care. *Ageing and Society*, 33(5), 888-907.
- Egdell, V., Bond, J., Brittain, K., & Jarvis, H. (2010). Disparate routes through support: negotiating the sites, stages and support of informal dementia care. *Health Place*, 16(1), 101-107.
- Eisenhardt, K. M. (1989). Building theories from case study research. *Academy of management review*, 14(4), 532-550.
- Elder, G. H., Johnson, M. K., & Crosnoe, R. (2003). The Emergence and Development of Life Course Theory. In J. T. S. M. J. Mortimer (Ed.), *Handbook of the Life Course. Handbooks of Sociology and Social*. Boston, MA.: Springer.
- Elliott, H. (1997). The use of diary methods in sociological research on health experience. *Sociological Research Online*, 2(2).
- Engster, D. (2007). *The heart of justice: Care ethics and political theory*. OUP:Oxford.
- Eriksen, S., & Gerstel, N. (2002). A labor of love or labor itself: Care work among adult brothers and sisters. *Journal of Family Issues*, 23(7), 836-856.
- Evandrou, M., Falkingham, J., Gomez-Leon, M., & Vlachantoni, A. (2018). Intergenerational flows of support between parents and adult children in Britain. *Ageing and Society*, 38(2), 321-351.
- Evers, A. (1995). Part of the welfare mix: The third sector as an intermediate area. *Voluntas: International Journal of Voluntary and Nonprofit Organizations*, 6(2), 159-182.
- Fabrigoule, C., Letenneur, L., Dartigues, J. F., Zarrouk, M., Commenges, D., & Barberger-Gateau, P. (1995). Social and leisure activities and risk of dementia: A prospective longitudinal study. *Journal of the American Geriatrics Society*, 43(5), 485-490.
- Faircloth, C. A., Boylstein, C., Rittman, M., Young, M. E., & Gubrium, J. (2004). Sudden illness and biographical flow in narratives of stroke recovery. *Sociology of Health & Illness*, 26(2), 242-261.
- Fast, J., Keating, N., Eales, J., Kim, C., & Lee, Y. (2020). Trajectories of family care over the lifecourse: evidence from Canada. *Ageing and Society*, 41(5), 1145-1162.
- Fast, J., Keating, N., Otfinowski, P., & Derksen, L. (2004). Characteristics of family/friend care networks of frail seniors. *Canadian journal on aging = La revue canadienne du vieillissement*, 23(1), 5-19.
- Faugier, J., & Sargeant, M. (1997). Sampling hard to reach populations. *Journal of Advanced Nursing*, 26(4), 790-797.

- Feld, S., Dunkle, R. E., & Schroepfer, T. (2004). Race/ethnicity and marital status in IADL caregiver networks. *Research on Aging, 26*(5), 531-558.
- Feld, S., Dunkle, R. E., Schroepfer, T., & Shen, H.-W. (2006). Expansion of elderly couples' IADL caregiver networks beyond the marital dyad. *International journal of aging & human development, 63*(2), 95-113. Retrieved from <http://search.ebscohost.com/login.aspx?direct=true&db=cmedm&AN=17137029&site=ehost-live>
- Feldman, S., Radermacher, H., Browning, C., Bird, S., & Thomas, S. (2008). Challenges of recruitment and retention of older people from culturally diverse communities in research. *Ageing & Society, 28*(04), 473-493.
- Ferlander, S. (2007). The Importance of Different Forms of Social Capital for Health. *Acta Sociologica, 50*(2), 115-128.
- Field, J. (2008). *Social capital* (2nd ed. ed.). London: Routledge.
- Finch, J. (1984). 'It's great to have someone to talk to': the ethics and politics of interviewing women. In C. Bell & H. Roberts (Eds.), *Social researching: politics, problems, and practice*. London: Routledge & Kegan Paul plc.
- Finch, J. (1989). *Family obligations and social change*. Cambridge: Polity Press.
- Finch, J., & Groves, D. (1983). *A Labour of love : women, work and caring*. London: Routledge & Kegan Paul.
- Finch, J., & Mason, J. (1993). *Negotiating family responsibilities*. London: Tavistock/Routledge.
- Findley, L. J. (2007). The economic impact of Parkinson's disease. *Parkinsonism & Related Disorders, 13*, S8-S12.
- Fine, M., & Glendinning, C. (2005). Dependence, independence or interdependence? Revisiting the concepts of 'care' and 'dependency'. *Ageing and Society, 25*, 602-621.
- Fingerman, K. L., Pillemer, K. A., Silverstein, M., & Sutor, J. J. (2012). The Baby Boomers' intergenerational relationships. *The Gerontologist, 52*(2), 199-209.
- Finkelstein, E. S., Reid, M. C., Kleppinger, A., Pillemer, K., & Robison, J. (2012). Are Baby Boomers Who Care for Their Older Parents Planning for Their Own Future Long-Term Care Needs? *Journal of Aging & Social Policy, 24*(1), 29-45.
- Flanagan, S. M., & Hancock, B. (2010). 'Reaching the hard to reach' - lessons learned from the VCS (voluntary and community Sector). A qualitative study. *BMC Health Services Research, 10*(1), 92.
- Flick, U. (2018). *An introduction to qualitative research*. London: Sage.
- Fontana, F., & Frey, J. H. (2008). The Interview. In N. K. Denzin & Y. S. Lincoln (Eds.), *Collecting and interpreting qualitative materials* (3rd ed.). London: Sage.
- Fotaki, M. (2010). Equity and choice in health care. Can they go hand in hand: Theory and evidence. *Sociology and Health and Illness, 32*(6), 898-913.
- Fotaki, M. (2014) What market-based patient choice can't do for the NHS: The theory and evidence of how choice. Centre for Health and Public Interest (CHPI). Retrieved from: <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.698.9761&rep=rep1&type=pdf>
- Freidson, E. (1988). *Profession of medicine : a study of the sociology of applied knowledge : with a new afterword*. Chicago: University of Chicago Press.
- Fu, Y. (2005). Measuring personal networks with daily contacts: a single-item survey question and the contact diary. *Social Networks, 27*(3), 169-186.
- Fukuyama, F. (1995). *Trust : the social virtues and the creation of prosperity*. London: Penguin, 1996.
- Gibson, G. (2016). 'Signposts on the journey'; medication adherence and the lived body in men with Parkinson's disease. *Social Science & Medicine, 152*, 27-34.
- Gibson, G., & Kierans, C. (2017). Ageing, masculinity and Parkinson's disease: embodied perspectives. *Sociology of Health & Illness, 39*(4), 532-546.
- Giddens, A. (1994). *Beyond left and right : the future of radical politics*. Cambridge: Polity Press.
- Gilleard, C. (2004). Cohorts and generations in the study of social change. *Social Theory & Health, 2*(1), 106-119.

- Glaser, K., Stuchbury, R., Tomassini, C., & Askham, J. (2008). The long-term consequences of partnership dissolution for support in later life in the United Kingdom. *Ageing & Society*, 28(3), 329-351.
- Glendinning, C. (2012). Home care in England: markets in the context of under-funding. *Health & Social Care in the Community*, 20(3), 292-299.
- Glendinning, C., Challis, D. J., Fernández, J.-L., Jacobs, S., Jones, K., Knapp, M., . . . Stevens, M. (2008). Evaluation of the Individual Budgets Pilot Programme. Final Report.
- Glendinning, C., Mitchell, W., & Brooks, J. (2014). Ambiguity in practice? Carers' roles in personalised social care in England. *Health & Social Care in the Community*, 23(1), 23-32.
- Goldberg, D. P. (1988). User's guide to the General Health Questionnaire. *Windsor*.
- Gomm, R., Hammersley, M., & Foster, P. (2000). *Case study method: key issues, key texts*. London:SAGE
- Graham, H. (1983). Caring: a labour of love. In J. Finch & D. Groves (Eds.), *A Labour of love : women, work and caring*. London: Routledge & Kegan Paul.
- Granovetter, M. (1973). The Strength of Weak Ties. *American Journal of Sociology*, 78(6), 1360-1380.
- Granovetter, M. (1983). The Strength of Weak Ties: A Network Theory Revisited. *Sociological Theory*, 1, 201-233.
- Grant, M. J., & Booth, A. (2009). A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Info Libr J*, 26(2), 91-108.
- Gray, A. (2009a). The social capital of older people. *Ageing & Society*, 29, 5-31.
- Gray, D. E. (2009b). *Doing research in the real world* (2nd ed. ed.). London: SAGE.
- Greenhalgh, T. (2009). Patient and public involvement in chronic illness: beyond the expert patient. *BMJ*, 338, b49.
- Greenland, J. & Barker A., The Differential Diagnosis of Parkinson's Disease. In T. Stoker & J. Greenland (Eds.), *Parkinson's Disease: Pathogenesis and Clinical Aspects*. Retrieved from <https://www.ncbi.nlm.nih.gov/books/NBK536722/>
- Groen-van de Ven, L., Smits, C., Span, M., Jukema, J., Coppoolse, K., de Lange, J., . . . Vernooij-Dassen, M. (2018). The challenges of shared decision making in dementia care networks. *International psychogeriatrics*, 30(6), 843-857.
- Groger, L., Mayberry, P. S., & Straker, J. K. (1999). What We Didn't Learn Because of Who Would Not Talk to Us. *Qualitative Health Research*, 9(6), 829-835.
- Guba, E. G. and Lincoln, Y. S. (1994) Competing paradigms in qualitative research. In N. K. Denzin and Y. S. Lincoln (eds), *Handbook of Qualitative Research*, 105–17. Thousand Oaks, CA: Sage.
- Guba, E. G., and Lincoln, Y.S. (2005) Paradigmatic controversies, contradictions, and emerging confluences. In N. K. Denzin and Y. S. Lincoln (eds), *Handbook of Qualitative Research* (3rd edn), 191–215. Thousand Oaks, CA: Sage.
- Haahr, A., Kirkevold, M., Hall, E.O., Ostergaard, K. (2011) Living with advanced Parkinson's Disease: a constant struggle with unpredictability *Journal of Advanced Nursing* 67: 2 408-417
- Haaxma, C., Bloem, B., Borm, G., Oyen, W., Leenders, K., Eshuis, S., Booij, J., Dluzen, D., Horstink, W. (2007) Gender differences in Parkinson's Disease *Journal of Neurology and Neurosurgical Psychiatry* 78 819-824
- Halpern, D. (2005). *Social capital*. Oxford: Polity.
- Ham, C. (2014). *Reforming the NHS from within. Beyond hierarchy, inspection and markets* Retrieved from London: www.kingsfund.org.uk/publications/
- Ham, C., Dixon, A., & Brooke, B. (2012). *Transforming the delivery of health and social care: the case for fundamental change*. Retrieved from London: www.kingsfund.org.uk/publications/
- Hammersley, M., & Traianou, A. (2012). *Ethics in qualitative research: Controversies and contexts*: London:Sage.

- Hand, A., Oates, L. L., Gray, W. K., & Walker, R. W. (2018). Understanding the Care Needs and Profile of People Living at Home With Moderate to Advanced Stage Parkinson Disease. *Journal of Geriatric Psychiatry and Neurology*, 31(5), 237-247
- Hand, A., Oates, L. L., Gray, W. K., & Walker, R. W. (2019). The role and profile of the informal carer in meeting the needs of people with advancing Parkinson's disease. *Aging Ment Health*, 23(3), 337-344.
- Hargreaves, S., Bath, P. A., Duffin, S., & Ellis, J. (2018). Sharing and empathy in digital spaces: qualitative study of online health forums for breast cancer and motor neuron disease (amyotrophic lateral sclerosis). *Journal of medical Internet research*, 20(6), e9709.
- Hendricks, V. M., Blanken, P., & Adriaans, N. (1992). *Snowball Sampling: A Pilot Study on Cocaine Use* Retrieved from Rotterdam:
- Henn, M., Weinstein, M., & Foard, N. (2006). A critical introduction to social research. (2nd Edition. ed.). London.: Sage Publications.
- Henwood, M., Larkin, M., & Milne, A. (2017). Seeing the Wood for the Trees. Carer related research and knowledge: A scopingreview. Retrieved from <https://www.scie-socialcareonline.org.uk/seeing-the-wood-for-the-trees-carer-related-research-and-knowledge-a-scoping-review/r/a110f00000rctcnaalxxaaacommentxxbbb>
- Hermanns, M. (2013). The invisible and visible stigmatization of Parkinson's disease. *Journal of the American Association of Nurse Practitioners*, 25(10), 563-566.
- Herod, A. (1999). Reflections on interviewing foreign elites: praxis, positionality, validity, and the cult of the insider. *Geoforum*, 30(4), 313-327.
- Higgins, C. A., McClean, R. J., & Conrath, D. W. (1985). The accuracy and biases of diary communication data. *Social Networks*, 7(2), 173-187. Retrieved from <http://www.scopus.com/inward/record.url?eid=2-s2.0-0347843589&partnerID=40&md5=012a1e7e35d4c918ca5835f1b46173fe>
- Hillcoat-Nallétamby, S., & Phillips, J. E. (2011). Sociological Ambivalence Revisited. *Sociology*, 45(2), 202-217.
- Hirst, M. (2004). *Health inequalities and informal care : end of project report*. York: Social Policy Research Unit, University of York.
- HM Government. (1999). *Caring about Carers: A National Strategy for Carers*. London: Department of Health.
- HM Government. (2008). *Carers at the heart of 21st century families and communities.' A caring system on your side. A life of your own'*. London: Department of Health.
- Equality Act, , (2010)*. TSO
- Hochschild, A. R. (1983). *The managed heart : commercialization of human feeling*. Berkeley ; London: University of California Press.
- Hollstein, B. (2011). Qualitative approaches. In P. J. Carrington & J. Scott (Eds.), *The SAGE handbook of social network analysis*. London: SAGE.
- Hollstein, B., Töpfer, T., & Pfeffer, J. (2020). Collecting egocentric network data with visual tools: A comparative study. *Network Science*, 8(2), 223-250.
- Holmes, A. G. D. (2020). Researcher Positionality--A Consideration of Its Influence and Place in Qualitative Research--A New Researcher Guide. *Shanlax International Journal of Education*, 8(4), 1-10.
- Hong, S.-I. (2009). Understanding Patterns of Service Utilization Among Informal Caregivers of Community Older Adults. *The Gerontologist*, 50(1), 87-99.
- Hopf, C. (2004). Research Ethics and Qualitative Research. In U. Flick, E. v. Kardorff, & I. Steinke (Eds.), *A companion to qualitative research* (pp. 334-339). London: SAGE.
- Houngaard, L., Pedersen, B., & Wagner, L. (2011). The daily living for informal caregivers with a partner with Parkinson's disease – an interview study of women's experiences of care decisions and self-management. *Journal of Nursing and Healthcare of Chronic Illness*, 3(4), 504-512.

- House, B. M., Chassie, M. B., & Bowling Spohn, B. (1990). Questioning: An Effective Ingredient in Effective Teaching. *The Journal of Continuing education in Nursing*, 21(5), 196-201.
- House, J. S., Umberson, D., & Landis, K. R. (1988). Structures and Processes of Social Support. *Annual Review of Sociology*, 14, 293-318.
- Hughes, C. (1994). From field notes to dissertation: analysing the stepfamily. In A. Bryman & R. Burgess (Eds.), *Analysing Qualitative Data*. London: Routledge.
- Humphries, R. (2011). *Social care funding and the NHS: An impending crisis*. London: King's Fund.
- Humphries, R., Thorlby, R., Holder, H., Hall, P., & Charles, A. (2016). *Social care for older people : home truths*. London:King's Fund.
- Information Commissioner's Office. (2018). *Guide to the General Data Protection Regulation*. Retrieved from <https://www.gov.uk/government/publications/guide-to-the-general-data-protection-regulation>
- Jacelon, C. S., & Imperio, K. (2005). Participant diaries as a source of data in research with older adults. *Qualitative health research*, 15(7), 991-997.
- Jacobs, M., Broese van Groenou, M. I., Aartsen, M. J., & Deeg, D. J. H. (2018). Diversity in Older Adults' Care Networks: The Added Value of Individual Beliefs and Social Network Proximity. *J Gerontol B Psychol Sci Soc Sci*, 73(2), 326-336.
- Jacobs, M., Van Tilburg, T., Groenewegen, P., & Broese Van Groenou, M. (2016). Linkages between informal and formal care-givers in home-care networks of frail older adults. *Ageing and Society*, 36(8), 1604-1624.
- Jaglal, S., Cockerill, R., Lemieux-Charles, L., Chambers, L. W., Brazil, K., & Cohen, C. (2007). Perceptions of the process of care among caregivers and care recipients in dementia care networks. *American journal of Alzheimer's disease and other dementias*, 22(2), 103-111.
- Jankovic, J. (2008). Parkinson's disease: clinical features and diagnosis. *J Neurol Neurosurg Psychiatry*, 79(4), 368-376.
- Jansen, L., Eecloo, L., Vanwing, A., & Schoenmakers, B. (2019). You never walk alone: An exploratory study of the needs and burden of an informal care group. *Health & social care in the community*, 27(2), 375-382.
- Jeffries, M., Mathieson, A., Kennedy, A., Kirk, S., Morris, R., Blickem, C., Vassilev, I. and Rogers, A. (2015). Participation in voluntary and community organisations in the United Kingdom and the influences on the self-management of long-term conditions. *Health Soc Care Community*, 23: 252-261.
- Jupp, V. (2006). *The SAGE dictionary of social research methods*. London: SAGE.
- Kahn, R., & Antonucci, T. (1980). Convoys over the life course: A life course approach In P. B. Baltes & O. Brim (Eds.), *Life span development and behaviour* (pp. 253–286.). New York: John Wiley & Sons, New York,.
- Kalia, L. V., & Lang, A. E. (2015). Parkinson's disease. *The Lancet (British edition)*, 386(9996), 896-912.
- Katbamna, S., Ahmad, W., Bhakta, P., Baker, R., & Parker, G. (2004). Do they look after their own? Informal support for South Asian carers. *Health & social care in the community*, 12(5), 398-406.
- Kawachi, I., Kim, D., Coutts, A., & Subramanian, S. V. (2004). Commentary: Reconciling the three accounts of social capital. *International Journal of Epidemiology*, 33(4), 682-690.
- Keating, N., & Dosman, D. (2009). Social capital and the care networks of frail seniors. *Can Rev Sociol*, 46(4), 301-318.
- Keating, N., & Eales, J. (2017). Social consequences of family care of adults: a scoping review. *International Journal of Care and Caring*, 1(2), 153-173.
- Keating, N., Kwan, D., Hillcoat-Nalletamby, S., & Burholt, V. (2015). *Evidence review of intergenerational relationships: Experiences and attitudes in the new millennium*. Retrieved from

- London:https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/458697/gs-15-23-future-ageing-intergenerational-relationships-er11.pdf
- Keating, N., Otfinowski, P., Wenger, C., Fast, J., & Derksen, L. (2003). Understanding the caring capacity of informal networks of frail seniors: a case for care networks. *Ageing and Society*, 23(1), 115-127.
- Keating, N., Swindle, J., & Foster, D. (2005). *The Role of Social Capital in Ageing Well*. Retrieved from Ottawa:http://profsopolisci.mcgill.ca/stolle/Publications_files/Sep2005socialcapitalinaction.pdf
- Kemp, C. L., Ball, M. M., & Perkins, M. M. (2013). Convoys of care: theorizing intersections of formal and informal care. *J Aging Stud*, 27(1), 15-29.
- Kingdon, C. (2005). Reflexivity: Not just a qualitative methodological research tool. *British Journal of Midwifery*, 13(10), 622-627.
- Kittay, E. F. (1999). *Love's Labor. essays on women, equality and dependency*. London and New York: Routledge.
- Klein, R. (1995). *The new politics of the National Health Service* (3rd ed.). London: Longman.
- Klein, R. (2019). *The new politics of the NHS* (7th ed.). London: CRC Press.
- Knapp, M., Bauer, A., Perkins, M., Snell, T. (2010). Building community capacity making an economic case. Retrieved from <http://www.pssru.ac.uk/pdf/dp2772.pdf>
- Knowles, S., Combs, R., Kirk, S., Griffiths, M., Patel, N., & Sanders, C. (2016). Hidden caring, hidden carers? Exploring the experience of carers for people with long-term conditions. *Health & Social Care in the Community*, 24(2), 203-213.
- Kouli, A., Torsney, K., & Kuan, W. (2018). Parkinson's Disease: Etiology, Neuropathology, and Pathogenesis. In T. Stoker & J. Greenland (Eds.), *Parkinson's Disease: Pathogenesis and Clinical Aspects*. Retrieved from <https://www.ncbi.nlm.nih.gov/books/NBK536722/>
- Kusow, Abdi M. (2003) Beyond Indigenous Authenticity: Reflections on the Insider/Outsider Debate in Immigration Research. *Symbolic Interaction*, vol. 26, no. 4, pp. 591-599.
- Kvale, S., & Brinkmann, S. (2009). *InterViews : learning the craft of qualitative research interviewing* (2nd ed.). Thousand Oaks ; London.: Sage Publications.
- Lapierre, T. A., & Keating, N. (2013). Characteristics and contributions of non-kin carers of older people: a closer look at friends and neighbours. *Ageing and Society*, 33(8), 1442-1468.
- Larkin, M., & Dickinson, H. (2011). Personalisation: what will the impacts be for carers? Accessed from <https://www.oneeastmidlands.org.uk/sites/default/files/library/LinkClick1.pdf>
- Larkin, M., & Milne, A. (2014). Carers and empowerment in the UK: a critical reflection. *Social Policy and Society*, 13(1), 25-38.
- Lauritzen, J., Bjerrum, M. B., Pedersen, P. U., & Sørensen, E. E. (2019). Support groups for carers of a person with dementia who lives at home: A focused ethnographic study. *Journal of Advanced Nursing*, 75(11), 2934-2942.
- Le Grand, J. (1991). Quasi-Markets and Social Policy. *The Economic Journal*, 101(408), 1256-1267.
- Lees, A. J., Hardy, J., & Revesz, T. (2009). Parkinson's disease. *The Lancet (British edition)*, 373.
- Leinonen, A. M. (2011). Adult children and parental care-giving: making sense of participation patterns among siblings. *Ageing and Society*, 31(2), 308-327.
- Lewis, J & West, A. (2014) Reshaping Social Care Services for Older People in England: Policy Development and the Problems of Achieving 'Good Care.'*Journal of Social Policy*, 43(1), 1-18.
- Lin, N. (1999). Building a Network Theory of Social Capital. *Connections*, 22(1), 28-51.
- Lindgren, C. L. (1996). Chronic sorrow in persons with Parkinson's and their spouses. *Scholarly Inquiry for Nursing Practice*, 10(4), 351-366.
- Lloyd, L. (2000). Caring about carers: only half the picture? *Critical Social Policy*, 20(1), 136-150.
- Lloyd, L. (2006). Call us carers: Limitations and risks in campaigning for recognition and exclusivity. *Critical Social Policy*, 26(4), 945-960.
- Long, J., Cunningham, F., and Brathwaite, J. (2013) Bridges, brokers and boundary spanners in collaborative networks: a systematic review. *BMC Health Services Research*. 13:158

- Lovatt, M., Bath, P. A., & Ellis, J. (2017). Development of trust in an online breast cancer forum: a qualitative study. *Journal of Medical Internet Research*, 19(5), e7471.
- Luescher, K., & Pillemer, K. (1998). Intergenerational ambivalence: A new approach to the study of parent-child relations in later life. *Journal of Marriage and the Family*, 60(2), 413-425.
- Lyons, K. S., Stewart, B. J., Archbold, P. G., & Carter, J. H. (2009). Optimism, Pessimism, Mutuality, and Gender: Predicting 10-Year Role Strain in Parkinson's Disease Spouses. *The Gerontologist*, 49(3), 378-387.
- Malley, J. and Fernandez, J.-L. (2010), 'Measuring quality in social care services: theory and practice', *Annals of Public and Cooperative Economics*, 81: 4, 559-82.
- Marin, A., & Hampton, K. N. (2007). Simplifying the personal network name generator: Alternatives to traditional multiple and single name generators. *Field methods*, 19(2), 163-193.
- Marmot, M. (2010). *Fair society, healthy lives : The Marmot review*. London: Marmot Review.
- Marmot, M. (2020). *Health Equity in England : The Marmot Review 10 Years On*. London: The Health Foundation.
- Marsden, P. V. (1990). Network Data and Measurement. *Annual Review of Sociology*, 16, 435-463.
- Marsden, P. V., & Campbell, K. E. (1984). Measuring tie strength. *Social Forces*, 63(2), 482-501.
- Martinez-Martin, P., Arroyo, S., Rojo-Abuin, J. M., Rodriguez-Blazquez, C., Frades, B., & de Pedro Cuesta, J. (2008). Burden, perceived health status, and mood among caregivers of Parkinson's disease patients. *Mov Disord*, 23(12), 1673-1680.
- Martínez-Martín, P., Forjaz, M. J., Frades-Payo, B., Rusiñol, A. B., Fernández-García, J. M., Benito-León, J., . . . Catalán, M. J. (2007). Caregiver burden in Parkinson's disease. *Movement Disorders*, 22(7), 924-931.
- Mason, J. (2002). *Qualitative researching*. London: SAGE.
- McCallister, L., & Fischer, C. (1978). A procedure for surveying personal networks. *Sociological Methods and Research*, 7, 13-1481.
- McKee, K. J., Philp, I., Lamura, G., Prouskas, C., Oberg, B., Krevers, B., . . . Szczerbinska, K. (2003). The COPE index--a first stage assessment of negative impact, positive value and quality of support of caregiving in informal carers of older people. *Aging Ment Health*, 7(1), 39-52.
- McKenzie, K., & Harpham, T. (2006). *Social capital and mental health*. London: Jessica Kingsley.
- McLaughlin D, Hasson F, Kernohan WG, et al. (2011) Living and coping with Parkinson's disease: Perceptions of informal carers. *Palliative Medicine*.25(2):177-182.
- Merz, E. M., & Gierveld, J. D. J. (2016). Childhood memories, family ties, sibling support and loneliness in ever-widowed older adults: quantitative and qualitative results. *Ageing & Society*, 36(3), 534-561.
- Milardo, R. (1987). Families and social networks: An overview of theory and methodology. In R. Milrado (Ed.), *Families and Social Networks*. Beverly Hills: Sage.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis : an expanded sourcebook* (2nd ed). London: Sage.
- Miller, D. A. (1981). The 'sandwich' generation: adult children of the aging. *Social Work*, 26(5), 419-423.
- Moen, P., & DePasquale, N. (2017). Family care work: a policy-relevant research agenda. *International Journal of Care and Caring*, 1(1), 45-62.
- Moen, P., & Spencer, D. (2006). Eight Converging Divergences in Age, Gender, Health, and Well-Being: Strategic Selection in the Third Age. In R. H. Binstock, L. K. George, S. J. Cutler, J. Hendricks, & J. H. Schulz (Eds.), *Handbook of Aging and the Social Sciences (Sixth Edition)* (pp. 127-144). Burlington: Academic Press.
- Moffat, S., Higgs, P., Rummery, K., & Jones, I. (2012). Choice, consumerism and devolution: Growing old in the welfare state(s) of Scotland, Wales and England. *Ageing and Society*, 32(5), 725-746.
- Molyneaux, V., Butchard, S., Simpson, J., & Murray, C. (2010). Reconsidering the term 'carer': a critique of the universal adoption of the term 'carer'. *Ageing and Society*, 31(3), 422-437. #

- Morris, R., Kirk, S., Kennedy, A., Vassilev, I., Mathieson, A., Jeffries, M., . . . Rogers, A. (2015). Connecting local support: a qualitative study exploring the role of voluntary organisations in long-term condition management. *Chronic illness*, 11(2), 140-155.
- Morse, J. M. (2001). Interviewing the Ill. In Gubrium, J. & J. A. Holstein (Eds.), *Handbook of Interview Research*, (pp. 317–330). Thousand Oaks, CA: Sage.
- Mulley, A. G., Trimble, C., & Elwyn, G. (2012). Stop the silent misdiagnosis: patients' preferences matter. *BMJ*, 345.
- National Audit Office. (2013) What are third sector organisations and their benefits for commissioners? Accessed on 1st Spetember 2014. <https://www.nao.org.uk/successful-commissioning/introduction/what-are-civil-society-organisations-and-their-benefits-for-commissioners/>
- National Audit Office. (2016). *Discharging older patients from hospital. HC 18*. Accessed on 1st Spetember 2020 www.nao.org.uk/report/discharging-older-patients-from-hospital/
- National Audit Office. (2018a). *Ministry of Housing, Communities and Local Government, Department of Health & Social Care and NHS England : The health and social care interface*: London : Dandy Booksellers Ltd,
- National Audit Office. (2018b). *Adult social care at a glance*. Retrieved from London: <https://www.nao.org.uk/wp-content/uploads/2018/07/Adult-social-care-at-a-glance.pdf>
- National Institute for Health and Care Excellence. (2017). Parkinson's disease in adults Nice guideline NG71. Retrieved from <https://www.nice.org.uk/guidance/ng71>.
- National Institute for Health and Care Excellence. (2020). Supporting adult carers NG150. Retrieved from [Supporting adult carers \(nice.org.uk\)](https://www.nice.org.uk/guidance/ng150)
- Needham, C. (2011). Personalization: From Story-line to Practice. *Social Policy & Administration*, 45(1), 54-68.
- Newbronner, L., Chamberlain, R., Bosanquet, K., Bartlett, C., Sass, B., & Glendinning, C. (2011). Keeping personal budgets personal: learning from the experiences of older people, people with mental health problems and their carers. Research Report. Adults' Services Report, 40 . Social Care Institute for Excellence , London.
- Nezlek, J. B. (2012). *Diary methods for personality and social psychology*. London: SAGE.
- NHS and Community Care Act (1990)*, HMSO
- NHS England. (2014a). Commissioning for Carers. Retrieved on 1st September 2021 <https://www.england.nhs.uk/commissioning/comm-carers/>
- NHS England. (2014b). NHS England's Commitment to Carers. Retrieved on 1st September 2021 <https://www.england.nhs.uk/commissioning/comm-carers/>
- NHS England. (2016). Toolkit for Carers. Retrieved on 1st September 2021 <https://www.england.nhs.uk/commitment-to-carers/carers-toolkit/>
- NHS England. (2019a). *NHS Long Term Plan*. Retrieved from London: <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf>
- NHS England. (2019b). *Universal Personalised Care Implementing the Comprehensive Model*. Retrieved from London: <https://www.england.nhs.uk/wp-content/uploads/2019/01/universal-personalised-care.pdf>
- NHS England. (2019c). *Progressive Neurological Conditions Toolkit* Retrieved from London: <https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2019/08/progressive-neuro-toolkit.pdf>
- Nijhof, G. J. (1995). Parkinson's Disease as a problem of shame in public appearance. *Sociology of Health & Illness*, 17(2), 193-205.
- Nolan, M. (2001). Working with family carers: towards a partnership approach. *Reviews in Clinical Gerontology*, 11(01), 91-97.
- Nolan, M., Grant, G., & Keady, J. (1996). *Understanding family care : a multidimensional model of caring and coping*. Buckingham: Open University Press.

- Nolan, M. R., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004). Beyond person-centred care: a new vision for gerontological nursing. *J Clin Nurs*, 13(3a), 45-53. doi:10.1111/j.1365-2702.2004.00926.x
- NPSA, & NRES. (2011). Information Sheets and Consent Forms Retrieved from http://www.nres.npsa.nhs.uk/applications/guidance/consent-guidance-and-forms/?esctl1431725_entryid62=67013
- Oakley, A. (1993). *Essays on women, medicine, and health*. Edinburgh: Edinburgh University Press.
- Office for National Statistics. (2001). *Social capital: a review of the literature*. Retrieved from <https://webarchive.nationalarchives.gov.uk/ukgwa/20160105160709/http://www.ons.gov.uk/ons/guide-method/user-guidance/social-capital-guide/the-social-capital-project/social-capital--a-review-of-the-literature.pdf>
- Office for National Statistics (2011, 24th June 2010). National Statistics Online-Ageing Retrieved 16th June 2011, from <http://www.statistics.gov.uk/ci/nugget.asp?ID=949>
- Office for National Statistics. (2014). *Health expectancies at birth and at age 65 in the United Kingdom*. Retrieved from <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/bulletins/healthexpectanciesatbirthandage65intheunitedkingdom/previousReleases>
- Office for National Statistics. (2017). Unpaid carers provide social care worth £57 billion. Retrieved from <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/articles/unpaidcarersprovidesocialcareworth57billion/2017-07-10>
- Oguh, O., Kwasny, M., Carter, J., Stell, B., & Simuni, T. (2013). Caregiver strain in Parkinson's disease: national Parkinson Foundation Quality Initiative study. *Parkinsonism & related disorders*, 19(11), 975–979.
- Okunoye, O., Schrag, A., Walters, K., & Marston, L. (2019). Trends in the incidence of Parkinson's disease between 2006 and 2016: Analysis of a large primary care database. *Journal of the neurological sciences*, 405, 339-340.
- Oliver, D., Foot, C., & Humphries, R. (2014). *Making our health and care systems fit for an ageing population*. London: King's Fund.
- Oppenheim, A. N. (1992). *Questionnaire Design, Interviewing and Attitude Measurement* (2Rev.ed. ed.): Pinter Publr.
- Orona, C. (1990). Temporality and identity loss due to Alzheimer's disease. *Social Science & Medicine*, 30(11), 1247-1256. Retrieved from <http://www.sciencedirect.com/science/article/pii/027795369090265T>
- Pahl, R., & Pevalin, D. J. (2005). Between family and friends: a longitudinal study of friendship choice. *The British journal of sociology*, 56(3), 433-450.
- Pahl, R., & Spencer, L. (2004). Personal Communities: Not Simply Families of Fate or Choice. *Current Sociology*, 52(2), 199-221.
- Pahl, R., & Spencer, L. (2010). Family, Friends, and Personal Communities: Changing Models-in-the-Mind. *Journal of Family Theory & Review* 2, (September), 197–210.
- Parkinson's UK. (2017). The incidence and prevalence of Parkinson's in the UK Results from the Clinical Practice Research Datalink Reference Report. Retrieved from: https://www.parkinsons.org.uk/sites/default/files/2018-01/Prevalence%20%20Incidence%20Report%20Latest_Public_2.pdf
- Parkinson's UK. (2019). *2019 UK Parkinson's Audit Summary report* Retrieved from London: <https://www.parkinsons.org.uk/sites/default/files/202007/CS3524%20Parkinson%27s%20UK%20Audit%20-%20Summary%20Report%202019.pdf>
- Parkinson's UK. (2020). *What is Parkinson's?* . Retrieved from <https://www.parkinsons.org.uk/information-and-support/what-parkinsons>

- Patton, M. (1990). *Qualitative evaluation and research methods* (2nd ed.). London: Sage.
- Patton, M. (1999). Enhancing the quality and credibility of qualitative analysis. *Health Serv Res*, 34(5 Pt 2), 1189-1208.]
- Patton, M. (2002). Two decades of developments in qualitative inquiry: A personal, experiential perspective. *Qualitative Social Work*, 1, 261-283.
- Pearlin, L. I., & Aneshensel, C. S. (1994). Caregiving: The unexpected career. *Social Justice Research*, 7(4), 373-390.
- Peek, M. K., & Lin, N. (1999). Age differences in the effects of network composition on psychological distress. *Soc Sci Med*, 49(5), 621-636.
- Pensions Act*, (2008). TSO
- Perry, B. L., & Pescosolido, B. A. (2010). Functional specificity in discussion networks: The influence of general and problem-specific networks on health outcomes. *Social Networks*, 32(4), 345-357.
- Perry, B. L., & Pescosolido, B. A. (2015). Social network activation: the role of health discussion partners in recovery from mental illness. *Social Science & Medicine*, 125, 116-128.
- Personal Social Services Research Unit. (2010). *National Evaluation of Partnerships for Older People Projects: final report*. Retrieved from London: Department of Health
- Phillipson, C. (2001). *The family and community life of older people : social networks and social support in three urban areas*. London: Routledge.
- Pickard, L. (2008). *Informal care for older people provided by their adult children: projections of supply and demand to 2041 in England: Report to the Strategy Unit and Department of Health*. Retrieved from London:
- Pickard, L. (2015). A growing care gap? The supply of unpaid care for older people by their adult children in England to 2032. *Ageing and Society*, 35(1), 96-123.
- Pickard, L., King, D., & Knapp, M. (2016). The 'visibility' of unpaid care in England. *Journal of Social Work*, 16(3), 263-282.
- Pickard, S. (2010). The 'Good Carer.' Moral Practices in Late Modernity. *Sociology*, 44(3), 471-487.
- Piercy, K. W., & Woolley, D. N. (2000). Negotiating worker-client relationships: A necessary step to providing quality home health care. *Home Health Care Services Quarterly*, 18(1), 1-24.
- Pinder, R. (1992). Coherence and incoherence: doctors' and patients' perspectives on the diagnosis of Parkinson's Disease. *Sociology of Health & Illness*, 14(1), 1-22.
- Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychol Aging*, 18(2), 250-267.
- Poel, G.M. (1993) Delineating personal support networks. *Social Networks*. 15, (1), 49-70.
- Poortinga, W. (2006). Social capital: An individual or collective resource for health? *Social Science & Medicine*, 62(2), 292-302.
- Pope, C., Ziebland, S., & Mays, N. (2000). Analysing qualitative data. *Bmj*, 320(7227), 114-116.
- Portes, A. (1998). Social Capital: Its origins and applications in modern sociology. *Annual Review of Sociology*, 24, 1-24.
- Portes, A. (1998). Social Capital: Its origins and applications in modern sociology. *Annual Review of Sociology*, 24, 1-24.
- Prell, C. (2012). *Social network analysis. History, theory and methodology*. London: Sage.
- Public Health England. (2015). Local action on health inequalities: improving health literacy to reduce health inequalities. Retrieved from:
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/460709/4a_Health_Literacy-Full.pdf
- Public Health England (2021) Caring as a social determinant of health: review of evidence. Findings from a rapid review of reviews and analysis of the GP Patient Survey Retrieved from:
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/971115/Caring_as_a_social_determinant_report.pdf

- Pustejovsky, J. E., & Spillane, J. P. (2009). Question-order effects in social network name generators. *Social Networks*, 31(4), 221-229.
- Putnam, R. (2000). *Bowling alone : the collapse and revival of American community*. London: Simon & Schuster.
- Putnam, R. (2004). Commentary: "Health by association": some comments. *Int J Epidemiol*, 33(4), 667-671.
- Putnam, R., Leonardi, R., & Nanetti, R. Y. (1993). *Making democracy work: civic traditions in modern Italy*. Princeton, N.J: Princeton University Press.
- Ray, R. A., & Street, A. F. (2005). Who's there and who cares: age as an indicator of social support networks for caregivers among people living with motor neurone disease. *Health & social care in the community*, 13(6), 542-552.
- Rasmussen, B., O'Connell, B., Dunning, P., & Cox, H. (2007). Young women with type 1 diabetes' management of turning points and transitions. *Qualitative health research*, 17(3), 300-310.
- Read, J., Cable, S., Löfqvist, C., Iwarsson, S., Bartl, G., & Schrag, A. (2019). Experiences of health services and unmet care needs of people with late-stage Parkinson's in England: A qualitative study. *PloS one*, 14(12).
- Riley, M. W. (1983). The Family in an Aging Society:A Matrix of Latent Relationships. *Journal of Family Issues*, 4(3), 439-454.
- Rimmer, L. (1983). The economics of work and caring. In J. Finch & D. Groves (Eds.), *A Labour of love : women, work and caring*. London: Routledge & Kegan Paul.
- Ritchie, J., & Spencer, L. (1994). Qualitative data analysis for applied policy research. In A. Bryman & R. G. Burgess (Eds.), *Analyzing qualitative data*. London ; New York: Routledge.
- Roberto, K. A., & Blieszner, R. (2015). Diverse Family Structures and the Care of Older Persons. *Can J Aging*, 34(3), 305-320.
- Robson, C. (2002). *Real world research : a resource for social scientists and practitioner-researchers*. Oxford, UK ; Cambridge, Mass., USA: Blackwell.
- Rodrigues, Ricardo Jorge and Glendinning, Caroline (2014) Choice, competition and care : developments in English social care and the impacts on providers and older users of home care services. *Social Policy & Administration*. pp. 649-664.
- Rodríguez-Madrid, M. N., Del Río-Lozano, M., Fernandez-Peña, R., Jiménez-Pernett, J., García-Mochón, L., Lupiañez-Castillo, A., & García-Calvente, M. D. M. (2018). Gender Differences in Social Support Received by Informal Caregivers: A Personal Network Analysis Approach. *International journal of environmental research and public health*, 16(1).
- Rodwell, M. K. (1998). *Social work, constructivist research* New York: Garland.
- Roth, A. (2018). Informal Caregiving and Network Turnover Among Older Adults. *The Journals of Gerontology: Series B*, 75(7), 1538-1547.
- Roth, A. (2020). Informal Caregiving and Social Capital: A Social Network Perspective. *Research on Aging*, 42(9-10), 272-280.
- Rowe, Wendy E. (2014) Positionality. In David Coghlan and Mary Brydon-Miller (Eds). *The Sage Encyclopaedia of Action Research*, Coghlan. London: Sage.
- Rowson, J., Broome, S., & Jones, A. (2010). *Connected Communities. How Social Networks Power and Sustain the Big Society*. London: RSA.
- Rutherford, A., Bowes, A., Mitchell, B., & Wu, Z. (2014). Networks of Informal Caring: A Mixed-Methods Approach. *Canadian Journal on Aging*, 33(4), 473-487.
- Ryan, L., Mulholland, J., & Agoston, A. (2014). Talking ties: Reflecting on network visualisation and qualitative interviewing. *Sociological Research Online*, 19(2), 1-12.
- Sandelowski, M. (2000). Combining Qualitative and Quantitative Sampling, Data Collection, and Analysis Techniques in Mixed-Method Studies. *Research in Nursing & Health*, 23(3), 246-255.

- Sanders, S. (2007). Experiences of rural male caregivers of older adults with their informal support networks. *Journal of gerontological social work*, 49(4), 97-115.
- Savage, O., & Pratt, B. (2013). *The history of UK civil society: Briefing paper 38* Retrieved from <https://www.intrac.org/wpcms/wp-content/uploads/2016/09/Briefing-Paper-38-The-history-of-UK-civil-society.pdf>
- Savin-Baden, M. (2004). Achieving reflexivity: Moving researchers from analysis to interpretation in collaborative inquiry. *Journal of Social Work Practice*, 18(3), 365-378.
- Savin-Baden, Maggi and Claire Howell (2013) *Major. Qualitative Research: The Essential Guide to Theory and Practice*. Oxford: Routledge,
- Schmeeckle, M., Giarrusso, R., Feng, D., & Bengtson, V. L. (2006). What makes someone family? Adult children's perceptions of current and former stepparents. *Journal of Marriage and Family*, 68(3), 595-610.
- Schneider, J. (2009). *Having epilepsy: the experience and control of illness*: Temple University Press.
- Schön, D. A. (1995). *Reflective practitioner : how professionals think in action* (New ed. ed.): Arena.
- Schrag, A., Hovris, A., Morley, D., Quinn, N., & Jahanshahi, M. (2006). Caregiver-burden in parkinson's disease is closely associated with psychiatric symptoms, falls, and disability. *Parkinsonism & Related Disorders*, 12(1), 35-41.
- Schwandt, T. A. (1994) Constructivist, interpretivist approaches to human inquiry. In N. K. Denzin and Y. S. Lincoln (eds), *Handbook of Qualitative Research*, 118–37. Thousand Oaks, California: Sage.
- Settersten, R. A. (2015). Relationships in Time and the Life Course: The Significance of Linked Lives. *Research in Human Development*, 12(3-4), 217-223.
- Settersten, R. A., & Gannon, L. (2005). Structure, Agency, and the Space Between: On the Challenges and Contradictions of a Blended View of the Life Course. *Advances in Life Course Research*, 10, 35-55.
- Sevenhuijsen, S. (2000). Caring in the third way: the relation between obligation, responsibility and care in Third Way discourse. *Critical Social Policy*, 20(1), 5-37.
- Sevenhuijsen, S. (1998). *Citizenship and the ethics of care: Feminist considerations on justice, morality and politics*. First Edition. London: Routledge.
- Shim, J. K. (2010). Cultural health capital: A theoretical approach to understanding health care interactions and the dynamics of unequal treatment. *J Health Soc Behav*, 51(1), 1-15.
- Silverman, D. (2005). *Doing qualitative research : a practical handbook* (2nd ed. ed.). London: SAGE.
- Silverstein, M., & Giarrusso, R. (2010). Aging and Family Life: A Decade Review. *Journal of Marriage and Family*, 72(5), 1039-1058.
- Simons, R. L. (1984). Specificity and substitution in the social networks of the elderly. *The International Journal of Aging and Human Development*, 18(2), 121-139.
- Sims-Gould, J., & Martin-Matthews, A. (2007). Family caregiving or caregiving alone: who helps the helper? *Canadian Journal on Aging*, 26, 27-45.
- Sims-Gould, J., & Martin-Matthews, A. (2008). Themes in family care-giving: implications for social work practice with older adults. *British Journal of Social Work*, 38(8), 1572-1587.
- Sims-Gould, J., & Martin-Matthews, A. (2010). We share the care: family caregivers' experiences of their older relative receiving home support services. *Health & social care in the community*, 18(4), 415-423.
- Small, M. L., & Sukhu, C. (2016). Because they were there: Access, deliberation, and the mobilization of networks for support. *Social Networks*, 47, 73-84.
- Smith, J., & Noble, H. (2016). Reviewing the literature. *Evid Based Nurs*, 19(1), 2-3. doi:10.1136/eb-2015-102252
- Smith, P. (1992). *The emotional labour of nursing : its impact on interpersonal relations, management and the educational environment in nursing*, London: Macmillan.
- Solimeo, S. (2008). Sex and Gender in Older Adults' Experience of Parkinson's Disease. *The journals of gerontology. Series B, Psychological sciences and social sciences*, 63(1), S42-S48.
- Solimeo, S. (2009). *With shaking hands : aging with Parkinson's disease in America's heartland*. New Brunswick, N.J. ; London: Rutgers University Press.

- Spencer, L., Ritchie, J., O'Connor, W., Morrell, G., & Ormston, R. (2014). Analysis in practice. In J. Ritchie, J. Lewis, C. McNaughton Nicholls, & R. Ormston (Eds.), *Qualitative research practice : a guide for social science students and researchers* (Second edition.). London: Sage Publications.
- Spiers, J. A. (2002). The interpersonal contexts of negotiating care in home care nurse-patient interactions. *Qualitative Health Research, 12*(8), 1033-1057.
- Spillman, B. C., & Pezzin, L. E. (2000). Potential and Active Family Caregivers: Changing Networks and the 'Sandwich Generation'. *The Milbank Quarterly, 78*(3), 347-374.
- Stake, R. E. (1995). *The art of case study research*. London: Sage Publications.
- Stanley-Hermanns, M., & Engebretson, J. (2014). Sailing Stormy Seas: The Illness Experience of Persons with Parkinson's Disease. *Qualitative Report, 15* (2), 340-369.
- Statham, J. (2011). Grandparents providing childcare. *London: Childhood Wellbeing Research Centre*.
- Stevens, L. (2010). Joining the Dots: How all the systems elements can connect to drive personalisation and co-production, involving individual social and community capacity. Retrieved from <http://www.thinklocalactpersonal.org.uk/BCC/caseStudy/BuildingTheBigSociety/ThinkPieces/index.cfm?parent=7821&child=8380>
- Steuerink, N., Westerhof, G. J., Bode, C., & Dittmann-Kohli, F. (2001). The personal experience of aging, individual resources, and subjective well-being. *J Gerontol B Psychol Sci Soc Sci, 56*(6), P364-373. doi:10.1093/geronb/56.6.p364
- Strauss, A. L., & Corbin, J. M. (1990). *Basics of qualitative research : grounded theory procedures and techniques*. Newbury Park, Calif.: Sage Publications.
- Suitor, J. J., Pillemer, K., & Keeton, S. (1995). When Experience Counts: The Effects of Experiential and Structural Similarity on Patterns of Support and Interpersonal Stress. *Social Forces, 73*(4), 1573-1588.
- Suitor, J., & Keeton, S. (1997). Once a friend, always a friend? Effects of homophily on women's support networks across a decade. *Social Networks, 19*(1), 51-62.
- Szinovacz, M. E., & Davey, A. (2007). Changes in adult child caregiver networks. *The Gerontologist, 47*(3), 280-295.
- Szreter, S., & Woolcock, M. (2004). Health by association? Social capital, social theory, and the political economy of public health. *International Journal of Epidemiology, 33*(4), 650-667.
- Taylor, D., & Bury, M. (2007). Chronic illness, expert patients and care transition. *Social Health Illn, 29*(1), 27-45.
- Taylor, S. E., & Lobel, M. (1989). Social comparison activity under threat: downward evaluation and upward contacts. *Psychological review, 96*(4), 569.
- Teahan, Á., Fitzgerald, C., & O'Shea, E. (2020). Family carers? perspectives of the Alzheimer Café in Ireland [version 2; peer review: 4 approved]. *HRB Open Research, 3*(18).
- Thabane, L., Ma, J., Chu, R., Cheng, J., Ismaila, A., Rios, L. P., . . . Goldsmith, C. H. (2010). A tutorial on pilot studies: the what, why and how. *BMC medical research methodology, 10*(1), 1-10.
- Thoits, P. (1985). Social support and psychological wellbeing: theoretical possibilities. In I. Sarason & B. Sarason (Eds.), *Social Support: Theory, Research and Applications*. Dordrecht: Martinus Nijhoff.
- Thoits, P. (1995). Stress, Coping, and Social Support Processes: Where Are We? What Next? *Journal of health and social behavior, 35*, 53-79.
- Thoits, P. (2011). Mechanisms linking social ties and support to physical and mental health. *Journal of Health and Social Behavior, 52*(2), 145-161.
- Thomas, S., Dalton, J., Harden, M., Eastwood, A., & Parker, G. (2017). *Updated meta-review of evidence on support for carers*. NIHR Journals Library.
- Thompson, C. (1999). Qualitative Research into Nurse Decision Making: Factors for Consideration in Theoretical Sampling. *Qualitative Health Research, 9*(6), 815-828.
- Tolkacheva, N., Van Groenou, M. B., De Boer, A., & Van Tilburg, T. (2011). The impact of informal care-giving networks on adult children's care-giver burden. *Ageing and Society, 31*(1), 34-51.

- Treece, E., & Treece, J. (1986). The pilot study and pretesting the instrument. *Elements of research in nursing* (4th ed., pp. 378-400). St. Louis, MO: Mosby.
- Tronto, J. (1993). *Moral Boundaries: A Political Argument for an Ethic of Care*. New York: Routledge.
- Twigg, J. (1989). Models of carers: how do social care agencies conceptualise their relationship with informal carers? *J Soc Policy*, 18(1), 53-66.
- Twigg, J. (1999). The spatial ordering of care: public and private in bathing support at home. *Sociology of Health & Illness*, 21(4), 381-400.
- Twigg, J., & Atkin, K. (1994). *Carers perceived : policy and practice in informal care*: Milton Keynes: Open University Press.
- Ungerson, C. (1983). Why do women care? In J. Finch & D. Groves (Eds.), *A Labour of love : women, work and caring* (pp. 69-86). London: Routledge & Kegan Paul.
- Ungerson, C. (1990). *Gender and caring : work and welfare in Britain and Scandinavia*. New York ; London: Harvester Wheatsheaf.
- Ungerson, C. (2000). Thinking about the production and consumption of long-term care in Britain: does gender still matter? *Journal of social policy*, 29(4), 623-643.
- Ungerson, C. (2003). Commodified care work in European Labour Markets. *European Societies*, 5(4), 377-396.
- Ungerson, C. (2005). Care, Work and Feeling. *The Sociological Review*, 53(2_suppl), 188-203.
- Ungerson, C. (2006). Gender, Care, and the Welfare State. In *Handbook of gender and women's studies*. (pp. 272-286). Thousand Oaks, CA, US: Sage Publications, Inc.
- van der Poel, M. G. M. (1993). Delineating personal support networks. *Social Networks*, 15(1), 49-70.
- van Meter, K. M. (1990). Sampling and cross-classification analysis in international social research. In *Comparative methodology: Theory and practice in international social research* (pp. 172-186). Thousand Oaks, CA, US: Sage Publications, Inc.
- van Teijlingen, E., & Hundley, V. (2001). The importance of pilot studies. *Social Research Update*(35), 1-4.
- Vassilev, I., Rogers, A., Blickem, C., Brooks, H., Kapadia, D., Kennedy, A., . . . Reeves, D. (2013). Social networks, the 'work' and work force of chronic illness self-management: a survey analysis of personal communities. *PLoS one*, 8(4), e59723.
- Vassilev, I., Rogers, A., Kennedy, A., & Koetsenruijter, J. (2014). The influence of social networks on self-management support: a metasynthesis. *BMC public health*, 14(1), 1-12.
- Vassilev, I., Rogers, A., Sanders, C., Kennedy, A., Blickem, C., Protheroe, J., . . . Morris, R. (2011). Social networks, social capital and chronic illness self-management: a realist review. *Chronic illness*, 7(1), 60-86.
- Vatter, S., McDonald, K. R., Stanmore, E., Clare, L., McCormick, S. A., & Leroi, I. (2018). A qualitative study of female caregiving spouses' experiences of intimate relationships as cognition declines in Parkinson's disease. *Age and Ageing*, 47(4), 604-610.
- Vlachantoni, A. (2019). Unmet need for social care among older people. *Ageing and Society*, 39(4), 657-684.
- Vlachantoni, A., Shaw, R., Willis, R., Evandrou, M., Falkingham, J., & Luff, R. (2011). Measuring unmet need for social care amongst older people. *Popul Trends*(145), 56-72.
- Vogt, W. P. (2005). *Dictionary of statistics & methodology : a nontechnical guide for the social sciences* (3rd ed. ed.). London: SAGE.
- Walker, A. (1983). Care for elderly people: a conflict between women and the state. In J. Finch & D. Groves (Eds.), *A Labour of love : women, work and caring*. London: Routledge & Kegan Paul.
- Wanless, D. (2004). *Securing good health for the whole population*: HM Stationery Office London.
- Wanless, D. (2006). *Securing good care for older people : taking a long-term view*. London: King's Fund.
- Ward, E., Barnes, M., & Gahagan, B. (2012). *Well-being in old age: findings from participatory research*. Brighton: SSPARC.
- Wasserman, S., & Faust, K. (1994). *Social network analysis : methods and applications*. Cambridge: Cambridge University Press.

- Wellman, B. (1979). The community question: The intimate network of East Yorkers. *American Journal of Sociology*, 84, 1201-1231.
- Wellman, B. (2000). Partners in illness: who helps when you are sick?. *Complementary and alternative medicine: Challenge and change*, 1, 143-162.
- Wellman, B. (2002). Little Boxes, Glocalization, and Networked Individualism. In: Tanabe, M., van den Besselaar, P., Ishida, T. (eds) *Digital Cities II: Computational and Sociological Approaches*. Digital Cities 2001. Lecture Notes in Computer Science, vol 2362. Springer, Berlin, Heidelberg.
- Wellman, B., & Wortley, S. (1990). Different Strokes from Different Folks: Community Ties and Social Support. *American Journal of Sociology*, 96(3), 558-588.
- Wenger, G. C. (1993). The formation of social networks: Self help, mutual aid, and old people in contemporary Britain. *Journal of Aging Studies*, 7(1), 25-40.
- Wenger, G. C. (1997). Social networks and the prediction of elderly people at risk. *Aging & Mental Health*, 1, 311-320.
- Wenger, G. C., & Burholt, V. (2001). Differences over time in older people's relationships with children, grandchildren, nieces and nephews in rural North Wales. *Ageing & Society*, 21(5), 567-590.
- West, M., & Hogan, K. F. (2020). Carers' experiences of dementia support groups: A qualitative exploration. *Counselling and Psychotherapy Research*, 20(1), 136-142.
- Widmer, E. D., Aeby, G., & Sapin, M. (2013). Collecting family network data. *International Review of Sociology*, 23(1), 27-46.
- Williams, S., & Keady, J. (2008). 'A stony road... a 19 year journey': 'Bridging' through late-stage Parkinson's disease. *Journal of Research in Nursing*, 13(5), 373-388.
- Williamson, C., Simpson, J., & Murray, C. D. (2008). Caregivers' experiences of caring for a husband with Parkinson's disease and psychotic symptoms. *Social Science & Medicine*, 67(4), 583-589.
- Wilson, P. M. (2001). A policy analysis of the Expert Patient in the United Kingdom: self-care as an expression of pastoral power? *Health Soc Care Community*, 9(3), 134-142.
- Woolcock, M. (1998). Social Capital and Economic Development: Toward a Theoretical Synthesis and Policy Framework. *Theory and Society*, 27(2), 151-208.
- Woolham, J., Steils, N., Daly, G., & Ritters, K. (2018). The impact of personal budgets on unpaid carers of older people. *Journal of Social Work*, 18(2), 119-141.
- Work and Families Act, (2006)*. TSO.
- World Health Organization. (1998). *Programme on mental health: WHOQOL user manual*. Retrieved from https://apps.who.int/iris/bitstream/handle/10665/77932/WHO_HIS_HSI_Rev.2?sequence=1
- Yeandle, S., Kröger, T., & Cass, B. (2012). Voice and choice for users and carers? Developments in patterns of care for older people in Australia, England and Finland. *Journal of European Social Policy*, 22(4), 432-445.
- Yeandle, S., & Wigfield, A. (Eds.). (2011). *New approaches to supporting carers' health and well-being: Evidence from the national carers' strategy demonstrator sites programme*. Leeds:Circle, University of Leeds.
- Yeo, A., Legard, R., Keegan, J., Ward, K., Mc Naughton Nicholls, C., & Lewis, J. (2014). In-depth interviews. In J. Ritchie, J. Lewis, C. McNaughton Nicholls, & R. Ormston (Eds.), *Qualitative research practice : a guide for social science students and researchers* ((Second edition.). London:Sage Publications.
- Yin, R. K. (2009). *Case study research : design and methods* (4th ed.) London: SAGE.

- Zarit, S. H., Todd, P. A., & Zarit, J. M. (1986). Subjective burden of husbands and wives as caregivers: a longitudinal study. *Gerontologist*, 26(3), 260-266.
- Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta psychiatrica scandinavica*, 67(6), 361-370.
- Zimmerman, D. H., & Wieder, D. L. (1977). The diary interview method. *Urban Life*, 5 (4), 479.