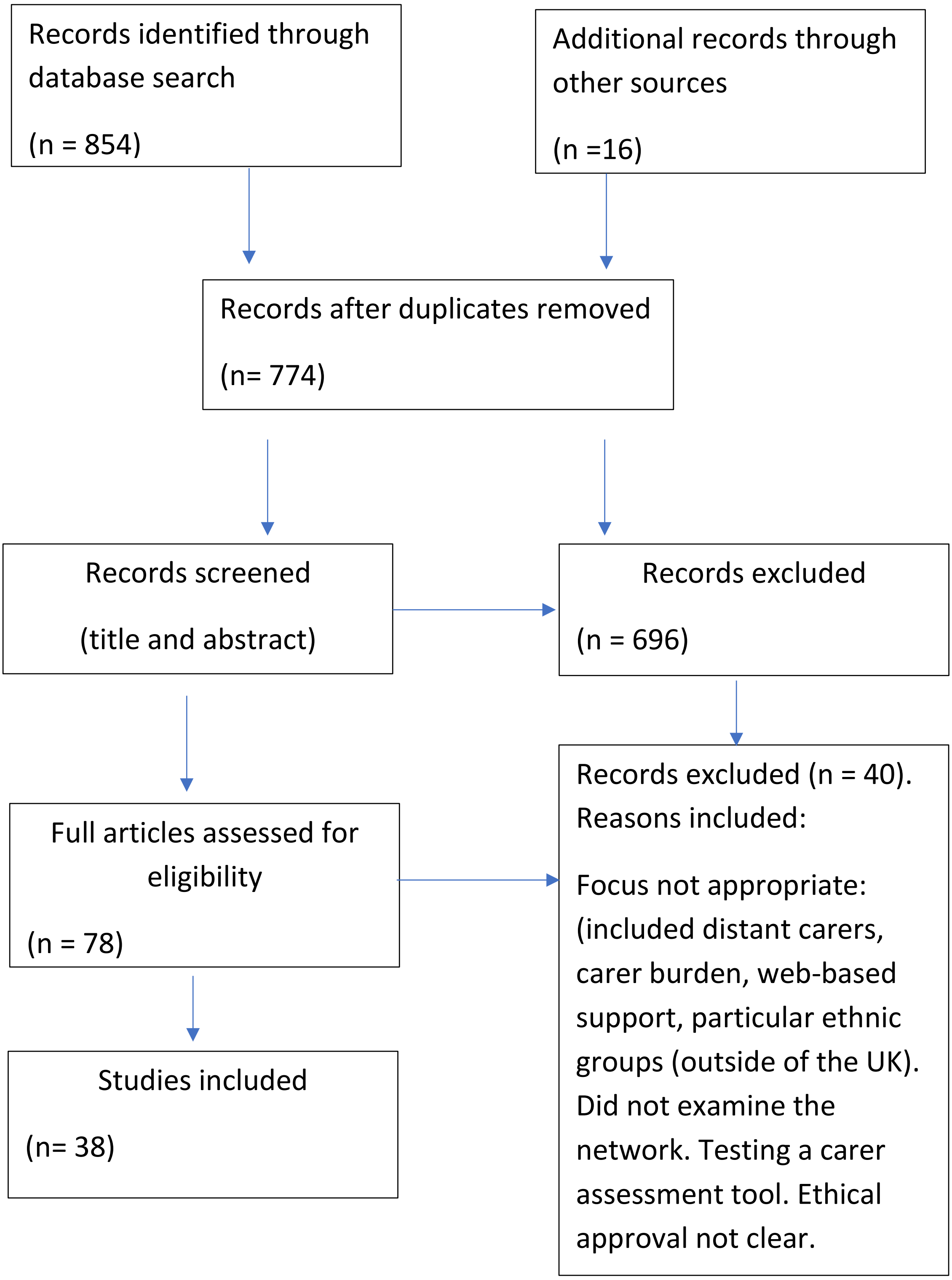
Appendices

Appendix 1: Literature Search PRISMA Diagram



Appendix 2: Summary of the Studies Included in the Systematised Review

Authors/Year	Country	Aim of study	Sample size	Methods	Key findings
Abendroth et al, (2014)	US	To explore the views and experiences of PD caregivers in peer-led support groups	Twenty carers of those with PD (all white, 17 female, mainly spouses and 3 adult daughters).	Qualitative. Grounded theory-semi structured interviews	Found that peer-led support groups for family caregivers of persons with Parkinson's disease were an important source of support-in relation to: Illness uncertainty; and broken connections with others. The intimate connections made are used to offer a lifeline to other carers.
Amaro (2017)	US	To examine the relationships between caregiver burden, relational conflict, individual contribution, and gratitude exchange between carers of aging parents and their siblings.	Fifty-four matched sibling pairs	Quantitative/CS. Dyadic data was collected through an online survey and data analysed using a series of actor– partner interdependence models.	Dimensions of gratitude were related to reduced carer burden, improved care-related conflict, and promotion of greater contribution to caregiving.
*The following are linked studies. Jacobs et al. (2016)	Netherlands	To examine the discussion of care between all potential informal–formal care-giver dyads in a care network and relate this to characteristics of the care recipient, the care network and the care-givers	Seventy-four Dutch older care recipients provided information on all carers who helped with five different types of tasks. Then 94 informal care-givers (including 11 volunteers) and 102 formal care-givers were also interviewed	Mixed methods. CS. Multi-level logistic regression was conducted on 2,150 informal–formal care-giver dyads	Findings revealed that in 26 per cent of all these dyads discussion on care occurred. This was more likely when both carers performed multiple types of tasks, the informal care-giver was residing and contact within the formal and the informal sub-network was higher.

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*Broese et al (2016)	Netherlands	Explored how structural and functional features overlap between formal and informal carers. To contribute to different types of mixed care networks. Also how these networks are associated with the care recipients' characteristics.	As above but did not include the volunteers.	Quantitative C/S. Descriptive statistics used to examine network size. The proportions of formal helpers, of contact and task overlap were the variables used to determine the network typology. A principal component analysis was undertaken	Four network types were evident: A small mixed care network, a small formal network, a large mixed network and a large formal networ
Jacobs et al. (2018)	Netherlands	To describe care network types, the variance of informal carers and examine associations with characteristics of community-dwelling older adults, including individual beliefs and network proximity.	A subsample of older care receivers (n=491) from the Longitudinal Aging Study Amsterdam	Quantitative. CS. Latent class analyses were applied in order to identify homogeneous subgroups of people with similar care networks. Multinomial regression analysis explored associations between network type and care receiver characteristics.	Findings; privately paid, coresidential, large informal, and publicly paid care network types were distinguished. The variations in informal care related to health, partner status, income, and proximity of children. Other nearby potential informal caregivers did not affect the network type. Perceived control of care was highest in the privately paid network

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*The following all form part of a longitudinal study Carpentier et al. (2008-2017)	Canada	To broadly examine the social/care networks of carers (both relatives and health professionals) of those with Alzheimer's diseases. along their whole illness trajectory.	Original cohort-60 caregivers purposively recruited from specialized cognition clinics. The majority of caregivers were women (71.7%) and most were either the wives (45.0%) or the daughters (25.0%) of the ill relative. Of the care-recipient, 27 were their caregiver's husband and 19 were their caregiver's mother. In the majority of cases (*n* = 41), the caregiver and the ill relative lived together.	Mixed methodology. L/S, started in 2003 combining social network and narrative analysis to elucidate the findings. Interviews were conducted every two years, until 2012. The numbers of participants decreased at each follow up period. Qualitative interviews were based on the caring trajectory, contextual aspects and the nature of the caregiving networks and experience of caring for an elderly person. Interviews were analysed using a standardised coding systems and the questions remained the same over time.	See below
*Carpentier et al. Ducharme (2008)	Canada	To examine network content in depth by examining carers structural, relational or cognitive barriers to support.	Fifty-two carer transcripts from the first wave of interviews were analysed	Data was analysed against a developed coding grid (based on barriers to service use identified from the literature). The period at the onset of the caregiver's involvement, the care context, their experiences, or those of other social network members in providing assistance to the care-recipient alongside the formal and	The delay in accessing services is related to the caregivers' practical knowledge and their social relations including the types of responses developed by their family networks.

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				informal resources used were the main areas of focus.	
Authors/Year	**Country**	**Aim of study**	**Sample size**	**Methods**	**Key findings**
*Carpentier et al. (2010)	Canada	To analyse the social processes associated with trajectories of care,	Sixty carer transcripts from the first wave of interviews were analysed	An interpretive approach based on network data and the analysis of action sequences as revealed by caregivers' narratives. A life course perspective was utilised to frame the findings	A typology of five pathways of entry into the care trajectory were developed and relate to the carers' and the care-recipients'-social networks. Typology based on 1. Families past experiences; 2. Watershed events; 3. Organisational effects; 4. Complex trajectories with gentle negotiations; 5. Complex trajectories with difficult negotiations
*Carpentier and Grenier (2012)	Canada	To examine the linkages between the informal and formal care networks	Original data set as above. Subset data from 4 carers was used. These carers reported the largest number of professionals in their support networks during the first three interviews.	Network analysis and a narrative fragment approach allowed integration of the two sets of data Details of the mechanisms of how each carer established relationships with resources outside the family are analysed.	Four detailed care trajectories (that illuminated successful links) are presented. Trust and recognition were key to establishing and maintaining supportive relationships.
*Brossard and Carpentier (2017)	Canada	To examine diagnosis in the Alzheimer' illness trajectory and its role in the mobilisation of a caregiving network.	Sixty carers as above	Qualitative analyses using a pre-defined coding system to uncover action sequences and the role of each actor in the patient's network . A study of the interviews with carers that detail what happened from the on-set of symptoms to the actual diagnosis, to examine	Different possibilities of intertwining between diagnosis and caregiving network mobilisation exist. The mobilisation of caregiving networks does not necessarily follow on from a diagnosis. The following may occur. The network may initiate the diagnosis; conversely network

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				processes and to synthesise them with the categories of observability and interpretation. Alongside this, the mobilisation of caregiving networks in relation to the timing of diagnosis was examined.	mobilisation may be prevented by it; or the diagnosis may have no direct impact whatsoever since diagnosis does not always relate to worsening symptoms, and therefore may not be a starting point for caregiving.
Authors/Year	**Country**	**Aim of study**	**Sample size**	**Methods**	**Key findings**
Dam et al. (2018)	Netherlands	To investigate multi-perspectives (including carers and their network members) on informal social support in dementia care networks.	Ten spousal caregivers of those with dementia, alongside 17 of their network members.	Qualitative. Data collected included a social network card and a semi-structured interview. The ecogram aimed to trigger subjective experiences regarding social support. Inductive content analysis generated key themes.	A mismatch was found between the carers and the network members on the need and provision of social support.
*The following all form part of an overall study *Egdell et al. (2010)	UK	To examines the complex negotiations made by carers and the different ways in which carers mobilise and draw upon their support networks.	Thirteen carers of those with dementia, at different stages of the carer trajectory	Qualitative. Semi-structured interviews and diary data were used. Grounded theory was used to analyse the data and generate themes.	Disparities/uneven support noted . This varied as carers utilise their available social, emotional, cultural and economic resources.
*Egdell (2012a)	UK	To identify the complex routes through support taken by informal caregivers for people with dementia in the development of their care networks	As above	As above	Three routes through support were identified: guided routes, organic routes, and chance routes. These routes are the outcomes from the resources that caregivers and expectations regarding the role of the informal caregiver.

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Authors/Year	Country	Aim of study	Sample size	Methods	Key findings
*Egdell (2012b)	UK	To explores the different ways carers for people with dementia negotiate their care-giving role across both organisational and spatial landscapes of care.	As above	As above	Three key issues emerged as influencing who provides care: relationships; geography and employment
Fast et al (2004)	Canada	To challenge the assumptions re: the characteristics of the care networks of the elderly	The networks of 1104 frail elderly living with a LTC were examined	Quantitative/CS. Using national survey data (which included social and community support data) a range of descriptive statistics are used to interrogate the composition of the networks.	The care networks of the frail elderly are diverse with family and friends working together to provide care. Varying network characteristics were found to explain the types and amounts of care received. Networks small in size with higher proportions of non-kin, male, and geographically distant members may lead to inadequate care.
Feld et al.2004	US	To examine the racial/ethnic variations in IADL carer network composition.	The data were from the first wave of the AHEAD survey, conducted in 1993-1994 White, Black, and Mexican American elders (n = 531 married and n =800 unmarried).	Quantitative. CS. Logistical regression statistics were used to analyse the data from the first wave of the Asset and Health Dynamics among the Oldest Old (AHEAD) survey	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 Black and White elderly care recipients. The findings did not indicate ethnic differences in either an individual or collective approach to the IADL care networks

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					of the married couples. including marital status, older persons' and spousal health, and financial resources.
Authors/Year	**Country**	**Aim of study**	**Sample size**	**Methods**	**Key findings**
Feld et al.2006	US	To analyse the composition of the care network beyond the spouse/partner dyad	A sub-group of data used- 427 Black and White couples (identified as spouses or partners- in which one was > 70 years and received help with an Instrumental Activity of Daily Living (IADL_-listed as preparing a hot meal; shopping for groceries; making a telephone call, and taking medications)	Quantitative. Descriptive and logistical regression statistics were used to analyse the data from the first wave of the Asset and Health Dynamics among the Oldest Old (AHEAD) survey	Nearly 20% had expanded networks. Regression showed expanded networks were significantly more likely when spouses had IADL or basic personal Activity of Daily Living (ADL) limitations, i.e higher needs and when care recipients were wives or had numerous IADL or ADL themselves; they were more common ($p < .10$) for couples with nearby daughters.
Groen-van de Ven et al. (2018)	Netherlands	To describe the challenges of shared decision making in dementia care networks.	Twenty three care networks (comprised of 23 people with dementia, 44 of their informal carers, and 46 of their professional caregivers).	A multi-perspective qualitative study using face-to-face interviews. Content analysis undertaken on the data.	Key themes: 1) adapting to diminishing independence, with changes in the care network, shifting decision-making roles and the need for anticipating future decisions; and 2) tensions in the network- need to agree on problems by information exchange in the care network .

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Authors/Year	Country	Aim of study	Sample size	Methods	Key findings
Hong (2009)	US	To identify patterns of service utilization among informal carers of elderly adults, with particular focus on those factors that explain heterogeneous variations in caregivers 'service use' patterns.	Caregiver data (n = 1,908) from the US, 2004 National Long-Term Care Survey was used.	Quantitative. CS. Using a latent class analysis (LCA) on the data, the study classified overall patterns of carer service use: The Network Episode Model and the modified Andersen model guided the analysis of carers' 'service use' patterns and social networks derived from determinants of these patterns	The LCA classified a hierarchical structure of service use patterns as follows: multiple service users, selective in-home service users, and light service users. Carer network compositions determined heterogeneity in service use patterns with care recipient- and carer-related needs also contributing.
Jaglal et al. (2007)	Canada	To investigate 4 community-based, non-profit dementia care networks to examine carer/care-recipient satisfaction with formal care services	A non-random convenience sample of regular users of network services was obtained. From this care recipients and carers (n = 267 dyads) were included.	Quantitative survey. CS.- Both univariate and bivariate relationships were analysed. The relationships between the process of care variables given as care recipient and carer sociodemographic and health characteristics, type of personal support network, service utilization, and social support were examined against the outcome variables as follows: satisfaction with quality and quantity of service provided; continuity and coordination of service provision; appropriateness, awareness, and availability of	Satisfaction of carer: care recipient dyad linked to family Drs understanding of dementia and ability to work with them to become aware of and accept services. Also, if carers received home support and the care recipients received emotional support from their social support network, they were more likely to be satisfied with their experiences with health care workers. In summary, increased awareness and provision of services were associated with more positive perceptions of network effectiveness.

				services; and experiences with family physicians	
Authors/Year	**Country**	**Aim of study**	**Sample size**	**Methods**	**Key findings**
Jansen et al (2019)	Belgium	To investigate the characteristics of an informal care group including; the obstacles they experience; their needs and desires and how they can be supported by general practitioners (GPs) and other professionals.	Nine informal care groups	Mixed methodology. CS. Qualitative interviews based on a questionnaire that was preapproved by the six Flemish official informal caregiver organisations. .Coding and thematic analysis was undertaken. Also a survey was conducted among 137 caregivers who were part of a group. Univariate analysis was used on this data	Informal care groups usually consist of close relatives of the patient, with often the partner of the patient as the main caregiver. Size depends on the size of the family and if more caregivers are in a group, the perceived burden of the individual caregiver decreases. The support of the other caregivers in the group increases capacity. The cooperation/ agreements are often spontaneously organised, and few problems are reported. A large variation was noted in the expectations of support from the GP ranging from availability in emergencies to information about the possibilities of formal home care.
Katbamna et al. (2004)	UK	A study of the experiences of carers in South Asian communities to examine the quality and quantity of informal support that was available in different types of households.	A total of 105 South Asian male and female carers were recruited. Participants were caring for people across age groups with physical and/or mental distress, and in some	A qualitative approach. Single sex focus groups and individual interviews were undertaken. Thematic and comparative analysis was used to analyse the transcripts.	Analysis suggests that, for several reasons, the main carer, irrespective of gender, had limited support both in nuclear and extended households. Also, the fear of obligation and societal attitudes towards disability prevented seeking

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			cases, with multiple and complex impairments.		and accepting help from wider social networks.
Authors/Year	**Country**	**Aim of study**	**Sample size**	**Methods**	**Key findings**
Keating and Dosman (2009)	Canada	To examine social capital in the families of frail older adults, and its benefits to the family	Data was taken from Statistics Canada (2002) General Social Survey on Aging and Social Support.The sample was taken from adults aged 65 and over who indicated that they had received assistance from family/friends (n = 2,407) in the previous year	Quantitative – CS. Care networks were determined from statistical analysis of those providing care. A social capital lens was used in examining the data	Six care networks identified: Lone spouse; Children at home; Spouse and children; Close kin and friends; Older diverse; Younger diverse. All had some close-kin members. This suggests bonding is integral to close-kin family connections and a necessary prerequisite to care networks. Friends and more distant kin allows for bridging to formal community resources, especially in the friends- and family network types
Lapierre and Keating (2013)	Canada	To investigate those who are non-kin (friends and neighbours) caring for an older adult with a particular focus on their characteristics and contributions	Using data from 324 non-kin carers in the 1996 General Social Survey of Canada,	Quantitative. CS. Analysis compared individual and relationship characteristics, care tasks and amount of care provided from the two.	Key findings: Relationship closeness explained differences. 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 more likely to assist with personal care, bills and banking, and transportation. Neighbours more

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					likely to assist with home maintenance.
Authors/Year	**Country**	**Aim of study**	**Sample size**	**Methods**	**Key findings**
Lauritzen et al. (2019)	Denmark	To understand carers (of those with dementia living at home) participation in support groups.	Twenty-five carers (19 women and 6 men including spouses, siblings, father/husband and an adult daughter). The relationships between the carer and the patient in-included spouses, female siblings, daughters, a daughter-in-law, and a neighbour	Ethnographic study. Participant observations at the support group and semi-structured interviews were undertaken with the carers. An inductive content analysis of the data was performed	Three themes were identified:: 1. Emotional well-being due to peer and family support; 2. Emotional sense of togetherness, despite hardships and 3. Emotional and ethical considerations in caregiving.
Leinonen (2011)	Finland	To explore working sibling carers' relationships with their siblings and the division of care	A subset of twenty carers (18 women) identified from the Finnish WoCaWo (Working Carers – Caring Workers) project.	This study uses data from qualitative interviews from those employed but who also provided regular care to older close kin and for this aspect those providing care to parents.	Division of care responsibilities is unequal. Three participation patterns were identified for the other siblings: 'absence', 'backup' and 'togetherness' (p308).
Ray and Street (2005)	Australia	To explore the social/ support networks of carers of people living with motor neurone disease (MND).	Eighteen primary carers of people with MND.	Ethnographic case study approach Eco mapping, observation and interviews were undertaken	Variation in size and composition of networks. Those in the older age groups had more diverse and consistent support systems while those younger had more variations in the strength of relationships and

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					declining support as caring became more demanding
Authors/Year	**Country**	**Aim of study**	**Sample size**	**Methods**	**Key findings**
Rodriguez et al. (2018)	Spain	To analyse the composition, structure, and function of carer support networks, to examine gender differences and the association between different network characteristics and self-perceived health among caregivers.	A convenience sample of 25 female and 25 male carers	C/S. A social network analysis (SNA) study. Descriptive analysis of the carers plus bivariate analyses for associations with self-perceived health were performed. Structural network analysis incl. density; degree centrality mean; betweenness centrality mean;	The personal networks of both genders were similar in structure but varied significantly in terms of composition and function. Men had broader, more diverse networks than women and received more support from alters outside the family circles, such as work colleagues and paid professionals and non-professionals. Women's networks were less diverse and mainly featured women with similar sociodemographic profiles to theirs and often from the same family
*The following all form part of an overall study *Roth (2018)	US	Tests whether the caregiving process is associated with network turnover in later life and whether the process is different for men and women	Two waves-data from those identifying as carers in the NSHAP (National Social Life, Health, and Aging Project survey-a nationally representative panel of older Americans). It identifies carers and contains detailed personal network measurements across waves. For this study n= 1528 participants.	Quantitative. L/S. Contacts of the carers were individually identified in each wave Therefore it was possible to document contact loss and addition. Poisson regression modelled rates of change.	Respondents transitioning into caregiving lost and added network contacts at higher rates than non-caregivers. However, carers giving care during both waves and those transitioning out of the role saw no significant levels of network turnover. There was minimal evidence of gender differences

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Authors/Year	Country	Aim of study	Sample size	Methods	Key findings
*Roth (2020)		Using a social capital lens to investigate if carers are more/less likely to exhibit bridging or bonding social capital when compared to non-carers.	As above	The data from HSHAP was analysed using network approaches on the core discussion network module at. waves 1 and 2 Networks from the different waves were compared and visual links were generated by Computer Assisted Programme Interviewing (CAPI). Respondents verified the data and interactions between network member were elucidated. Social capital potential, was determined as a proxy from those who were not directly/poorly connected with other members in the network.and were considered a bridging tie Respondents were considered to exhibit bonding social capital when., every network member was connected to at least one other member.	Despite possible constraints when transitioning into caring, carers are more likely to develop the ability to bridge social ties within their personal networks than non-carers, At later stages they do not differ from non-carers in terms of network change.
Rutherford et al., (2014)	UK	To explore networks of informal caring	British Household Panel Survey (BHPS, 2006) (n =5429). Selected from this are those identifying as a carer >50 years old and any care	A mixed-methods approach.. Using quantitative data from the BHPS together with qualitative interviews.	Four types of care network were characterised from the findings. 1.Care from spouse within the household. 2. Care from child(ren)

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			they provide within or outside the household. Carers were matched to care recipients within households to map informal care relationships Also interviews with 25 households. including both older people (n=22) and informal carers (n=11).		outside the household (a) while living alone (b) while living with others. (3) Care from children living within household. 4) Other living arrangements. In most cases the care networks had a strong core, and one primary informal carer-a spouse or a child. A secondary layer of informal support included a mix of children, other family, friends, neighbours, or others in the wider community. Where older people have moved in later life, particularly those moving in with children, this secondary support network may be missing.
Authors/Year	**Country**	**Aim of study**	**Sample size**	**Methods**	**Key findings**
Sanders (2007)	US	To understand the experience of male carers accessing support from their informal networks.	Twenty male carers (17, husbands and 3 sons, with 15 providing care at home, and the other 5 of the care recipients in residential care). Care recipients had progressive dementia and another LTC. All were providing care for a female, except for one son who was providing care for his father.	Qualitative phenomenological study with– 2 semi-structured interviews,	Two overarching areas were illuminated. 1. The perceptions of the male caregivers about the willingness of their informal support networks to provide caregiving assistance and (2) Willingness of the male caregivers to ask their informal support networks for assistance.

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Authors/Year	Country	Aim of study	Sample size	Methods	Key findings
*The following all form part of an overall study *Sims-Gould and Martin-Matthews (2007)	Canada	To examine the relationship between different family carers and their helpers.	Data from 250 individuals with caring responsibilities for at least one older person.	Quantitative. CS. Data taken from the Work and Eldercare Research group of CARNET (Canadian Aging Research Network). Statistical analysis – used to examine the data.	Findings extend Kahn & Antonucci's convoys of social support model (1981) and Cantor's model of social care (1991) by uncovering the dimensions of helping and caring and the distinction between direct and assistive help.
*Sims-Gould and Martin-Matthews (2008)	Canada	To examine the provision of care to an older relative by adult children.	Data collected from fifty-five CARNET respondents	Qualitative data analysis of verbatim data (responses to open-ended questions) from the CARNET research.	Five themes, identified: 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
Sims-Gould and Martin-Matthews (2010)	Canada	To examine family carers' experiences of the home support services received by their elderly relatives.	Data collected from 56 family carers	Qualitative- using in-depth semi-structured interviews	Dissatisfaction with instrumental aid provided by home support workers was expressed and affective support for the care-recipient was important. Assistive care (care provided to the carer by the paid home support and vice versa)- three key themes emerged: caring together, care management, and quality assurance and monitoring

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Authors/Year	Country	Aim of study	Sample size	Methods	Key findings
Szinovacz and Davey (2007)	US	To address changes in adult child carer networks over a 2-year period.	Pooled data from Waves 1 through to 5 of the Health and Retirement Study. From this, examining adult child carers, there were a total of 1,577 care occasions for analyses pertaining to changes in any adult child caregiver and 1,457 care occasions for change in the primary caregiver	Quantitative. L/S. Changes were assessed in any adult child caregiver as well as in the primary adult child caregiver networks. Statistical analyses used descriptive and regression analyses.	Over 50% of all adult-child care networks, including more than 25% of primary adult child caregivers, changed between waves. Gender composition of the caregiver network, availability of other adult child caregivers with the socioeconomic context, carer abilities, resources, and burden all were factors linked to change.
Teahan et al. (2020)	ROI	To investigate family carers' perspectives of Alzheimer Cafés and the benefits of attendance.	Family carers of people with dementia (5 spousal carers and 4 adult child) who were currently attending or had attended an Alzheimer Café in the preceding six months.	Qualitative. Semi-structured interviews were conducted with Bronfenbenner 's (1979) ecological framework as a guide. Thematic analysis generated key themes.	Community, atmosphere, activity and information were described as core features of the Alzheimer Café
Tolkacheva et al. (2011)	Netherlands	To assess how characteristics of the informal care-giving network affect the adult child's care-giver burden..	Carers (n-602) who were assisting their older parents reported on parental and personal characteristics, care activities, experienced burden and characteristics of other informal carers.	Quantitative.CS. To assess the relative impact of the informal care-giving network characteristics on the care-giver burden, a path model was used.	Lower carer burden was evident when the informal care network size was larger, when more tasks were shared across the network, when sharing care was for a longer period, and when there were no disagreements with the other members of the network

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West and Hogan (2020)	US	To evaluate, from a carer perspective, a dementia support group, in relation to protective measures including social and emotional support,	Informal carers (n=14) of dementia patients were interviewed about their experiences of attending dementia support groups	Qualitative. The interviews were transcribed verbatim and subject to thematic analysis.	Carer attendance at the group was associated with subjective well-being and the social support was stimulating and supportive. Participants valued sharing their experiences of being a carer with other members and finding out about resources.

Appendix 3: Initial Data Collection Tools

NETWORK DATA

INTERVIEW 1
Details Interview Date………………………………. Participant……………………………………… Participant Identifier………………………

	Question 1	Name 1	Name 2	Name 3	Name 4	Name 5	Name 6
1a	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?						
1b	What is the basis of your relationship? Family/Friend/neighbour/colleague/qualified/unqualified health worker/volunteer						
1c	How close is your relationship? 1) Extremely close 2) close 3)not close at all						
1d	How frequently do you have face to face contact? Daily/ Weekly/Monthly/ Every few months/Yearly or longer						
1e	How frequently do you have telephone contact? Daily/ Weekly/Monthly/ Every few months/Yearly or longer						
1f	How frequently do you have contact via other electronic means: SMS/ Email / Facebook/Other social networking? Daily/ Weekly/Monthly/ Every few months/Yearly or longer						
1g	How long (in minutes) would it take for this person to get to you?						

Appendix 3: Initial Data Collection Tools

NETWORK DATA

INTERVIEW 1
Details Interview Date………………………………. Participant……………………………………… Participant Identifier………………………

	Question 2	Name 1	Name 2	Name 3	Name 4	Name 5	Name 6
2a	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?						
2b	What is the basis of your relationship? Family/Friend/neighbour/colleague/qualified/unqualified health worker/volunteer						
2c	How close is your relationship? 1) Extremely close 2) close 3)not close at all						
2d	How frequently do you have face to face contact? Daily/ Weekly/Monthly/ Every few months/Yearly or longer						
2e	How frequently do you have telephone contact? Daily/ Weekly/Monthly/ Every few months/Yearly or longer						
2f	How frequently do you have contact via other electronic means: SMS/ Email / Facebook/Other social networking? Daily/ Weekly/Monthly/ Every few months/Yearly or longer						
2g	How long (in minutes) would it take for this person to get to you?						

N.B. If cares from a distance –ask in relation to recipient of care

Appendix 3: Initial Data Collection Tools

NETWORK DATA

INTERVIEW 1
Details Interview Date………………………………. Participant……………………………………… Participant Identifier………………………

	Question 3	Name 1	Name 2	Name 3	Name 4	Name 5	Name 6
3a	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?						
3b	What is the basis of your relationship? Family/Friend/neighbour/colleague/qualified/unqualified health worker/volunteer						
3c	How close is your relationship? 1) Extremely close 2) close 3)not close at all						
3d	How frequently do you have face to face contact? Daily/ Weekly/Monthly/ Every few months/Yearly or longer						
3e	How frequently do you have telephone contact? Daily/ Weekly/Monthly/ Every few months/Yearly or longer						
3f	How frequently do you have contact via other electronic means: SMS/ Email / Facebook/Other social networking? Daily/ Weekly/Monthly/ Every few months/Yearly or longer						
3g	How long (in minutes) would it take for this person to get to you?						

N.B. If cares from a distance –ask in relation to recipient of care

Appendix 3: Initial Data Collection Tools

NETWORK DATA

INTERVIEW 1

Details Interview Date………………………………. Participant……………………………………… Participant Identifier………………………

	Question 4	Name 1	Name 2	Name 3	Name 4	Name 5	Name 6
4a	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?						
4b	What is the basis of your relationship? Family/Friend/neighbour/colleague/qualified/unqualified health worker/volunteer						
4c	How close is your relationship? 1) Extremely close 2) close 3)not close at all						
4d	How frequently do you have face to face contact? Daily/ Weekly/Monthly/ Every few months/Yearly or longer						
4e	How frequently do you have telephone contact? Daily/ Weekly/Monthly/ Every few months/Yearly or longer						
4f	How frequently do you have contact via other electronic means: SMS/ Email / Facebook/Other social networking? Daily/ Weekly/Monthly/ Every few months/Yearly or longer						
4g	How long (in minutes) would it take for this person to get to you?						

Appendix 3: Initial Data Collection Tools

NETWORK DATA

INTERVIEW 1

Details Interview Date………………………………. Participant…………………………………… Participant Identifier………………………

	Question 5	Name 1	Name 2	Name 3	Name 4	Name 5	Name 6
5a	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?						
5b	What is the basis of your relationship? Family/Friend/neighbour/colleague/qualified/unqualified health worker/volunteer						
5c	How close is your relationship? 1) Extremely close 2) close 3)not close at all						
5d	How frequently do you have face to face contact? Daily/ Weekly/Monthly						
5e	How frequently do you have telephone contact? Daily/ Weekly/Monthly/ Every few months/Yearly or longer						
5f	How frequently do you have contact via other electronic means: SMS/ Email / Facebook/Other social networking? Daily/ Weekly/Monthly/ Every few months/Yearly or longer						
5g	How long (in minutes) would it take for this person to get to you?						

Appendix 3: Initial Data Collection Tools

NETWORK DATA

INTERVIEW 1

Details Interview Date………………………………. Participant……………………………………… Participant Identifier………………………

	Question 6	Name 1	Name 2	Name 3	Name 4	Name 5	Name 6
6a	Who are the people in your life with whom you discuss important matters?						
6b	What is the basis of your relationship? Family/Friend/neighbour/colleague/qualified/unqualified health worker/volunteer						
6c	How close is your relationship? 1) Extremely close 2) close 3)not close at all						
6d	Does this person cause you problems or difficulties? 1)Often 2) sometimes 3) never						
6e	How frequently do you have face to face contact? Daily/ Weekly/Monthly/ Every few months/Yearly or longer						
6f	How frequently do you have telephone contact? Daily/ Weekly/Monthly/ Every few months/Yearly or longer						
6g	How frequently do you have contact via other electronic means: SMS/ Email / Facebook/Other social networking? Daily/ Weekly/Monthly/ Every few months/Yearly or longer						
6h	How long (in minutes) would it take for this person to get to you?						

Appendix 3: Initial Data Collection Tools

NETWORK DATA

INTERVIEW 1

Details Interview Date………………………………. Participant……………………………………… Participant Identifier………………………

	Question 7	Name 1	Name 2	Name 3	Name 4	Name 5	Name 6
7a	Who, among all of 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?						
7b	What is the basis of your relationship? Family/Friend/neighbour/colleague/qualified/unqualified health worker/volunteer						
7c	How close is your relationship? 1) Extremely close 2) close 3)not close at all						
7d	Does this person cause you problems or difficulties? 1)Often 2) sometimes 3) never						
7e	How frequently do you have face to face contact? Daily/ Weekly/Monthly/ Every few months/Yearly or longer						
7f	How frequently do you have telephone contact? Daily/ Weekly/Monthly/ Every few months/Yearly or longer						
7g	How frequently do you have contact via other electronic means: SMS/ Email / Facebook/Other social networking? Daily/ Weekly/Monthly/ Every few months/Yearly or longer						
7h	How long (in minutes) would it take for this person to get to you?						

Appendix 3: Initial Data Collection Tools

NETWORK DATA

INTERVIEW 1

Details Interview Date………………………………. Participant……………………………………… Participant Identifier………………………

	Question 8	Name 1	Name 2	Name 3	Name 4	Name 5	Name 6
8a	Who, among all of the people in your life, do you talk to about the health of the person you care for?						
8b	What is the basis of your relationship? Family/Friend/neighbour/colleague/qualified/unqualified health worker/volunteer						
8c	How close is your relationship? 1) Extremely close 2) close 3)not close at all						
8d	Does this person cause you problems or difficulties? 1)Often 2) sometimes 3) never						
8e	How frequently do you have face to face contact? Daily/ Weekly/Monthly/ Every few months/Yearly or longer						
8f	How frequently do you have telephone contact? Daily/ Weekly/Monthly/ Every few months/Yearly or longer						
8g	How frequently do you have contact via other electronic means: SMS/ Email / Facebook/Other social networking? Daily/ Weekly/Monthly/ Every few months/Yearly or longer						
8h	How long (in minutes) would it take for this person to get to you?						

Appendix 3: Initial Data Collection Tools

NETWORK DATA

INTERVIEW 1

Details Interview Date………………………………. Participant……………………………………… Participant Identifier………………………

	Question 9		Name 1	Name 2	Name 3	Name 4	Name 5	Name 6
9a	Who, among all of the people in your life, do you talk to about your caring role ?							
9b	What is the basis of your relationship? Family/Friend/neighbour/colleague/qualified/unqualified health worker/volunteer							
9c	How close is your relationship? 1) Extremely close 2) close 3)not close at all							
9d	Does this person ever cause you problems or difficulties? 1)Often 2) sometimes 3) never							
9e	How frequently do you have face to face contact? Daily/ Weekly/Monthly/ Every few months/Yearly or longer							
9f	How frequently do you have telephone contact? Daily/ Weekly/Monthly/ Every few months/Yearly or longer							
9g	How frequently do you have contact via other electronic means: SMS/ Email / Facebook/Other social networking? Daily/ Weekly/Monthly/ Every few months/Yearly or longer							
9h	How long (in minutes) would it take for this person to get to you?							
9i	What is the nature of the support?							
	Discussion/listening	1) Yes 2) No						
	Emotional	1) Yes 2) No						
	Information/ advice	1) Yes 2) No						
	Instrumental	1) Yes 2) No						
	Financial	1) Yes 2) No						

Appendix 3: Initial Data Collection Tools

NETWORK DATA

INTERVIEW 1

Details Interview Date………………………………. Participant……………………………………… Participant Identifier………………………

	Question 10 ALL EXTRA		Name 1	Name 2	Name 3	Name 4	Name 5	Name 6
10a	Who are the people that you can count on to support you in in providing care?							
10b	What is the basis of your relationship? Family/Friend/neighbour/colleague/qualified/unqualified health worker/volunteer							
10c	How close is your relationship? 1) Extremely close 2) close 3)not close at all							
10d	Does this person ever cause you problems or difficulties? 1)Often 2) sometimes 3) never							
10e	How frequently do you have face to face contact? Daily/ Weekly/Monthly/ Every few months/Yearly or longer							
10f	How frequently do you have telephone contact? Daily/ Weekly/Monthly/ Every few months/Yearly or longer							
10g	How frequently do you have contact via other electronic means: SMS/ Email / Facebook/Other social networking? Daily/ Weekly/Monthly/ Every few months/Yearly or longer							
10h	How long (in minutes) would it take for this person to get to you?							
10i	What is the nature of the support?							
	Discussion/listening	1) Yes 2) No						
	Emotional	1) Yes 2) No						
	Information/advice	1) Yes 2) No						
	Instrumental	1) Yes 2) No						
	Financial	1) Yes 2) No						

Appendix 3: Initial Data Collection Tools

COPE QUESTIONNAIRE

IN GENERAL WOULD YOU SAY YOUR HEALTH IS:

Very good ☐ Good ☐ Fair ☐

Poor ☐ Very poor ☐

WHAT IS YOUR RELATIONSHIP TO THE PERSON YOU CARE FOR?

Spouse/Partner	☐	Sibling	☐
Child	☐	Daughter or Son-in-law	☐
Other Family	☐	Friend/Neighbour	☐

YOUR GENDER:

Male ☐ Female ☐

Appendix 3: Initial Data Collection Tools

YOUR OCCUPATIONAL STATUS:

Employed full-time	☐	Employed part-time	☐
Retired	☐	Unemployed	☐
Full-time Study	☐		

WHERE DO YOU AND THE PERSON YOU CARE FOR LIVE?

In the same household ☐

In different households but the same building ☐

Within walking distance ☐

Within 10 minutes drive/bus or train journey ☐

Within 30 minutes drive/bus or train journey ☐

Within 1hours drive/bus or train journey ☐

Over 1hours drive/bus or train journey ☐

Appendix 3: Initial Data Collection Tools

COPE INDEX

(1) Overall, do you feel well supported in your role of caregiver?

Always ☐ Often ☐ Sometimes ☐ Never ☐

(2) Do you feel you cope well as a caregiver?

Always ☐ Often ☐ Sometimes ☐ Never ☐

(3) Do you find caregiving too demanding?

Always ☐ Often ☐ Sometimes ☐ Never ☐

(4) Does caregiving cause difficulties in your relationships with friends?

Always ☐ Often ☐ Sometimes ☐ Never ☐ N/A ☐

(5) Does caregiving have a negative effect on your physical health?

Always ☐ Often ☐ Sometimes ☐ Never ☐

(6) Does caregiving cause difficulties in your relationship with your family?

Always ☐ Often ☐ Sometimes ☐ Never ☐ N/A ☐

(7) Does caregiving cause you financial difficulties?

Always ☐ Often ☐ Sometimes ☐ Never ☐

(8) Do you feel trapped in your role as a caregiver?

Always ☐ Often ☐ Sometimes ☐ Never ☐

Appendix 3: Initial Data Collection Tools

(9) Do you feel well supported by your friends and/or neighbours?

Always ☐ Often ☐ Sometimes ☐ Never ☐ N/A ☐

(10) Do you find caregiving worthwhile?

Always ☐ Often ☐ Sometimes ☐ Never ☐

(11) Do you feel well supported by your family?

Always ☐ Often ☐ Sometimes ☐ Never ☐ N/A ☐

(12) Do you have a good relationship with the person you care for?

Always ☐ Often ☐ Sometimes ☐ Never ☐

(13) Do you feel well supported by health and social services?

(for example, public, private, voluntary)

Always ☐ Often ☐ Sometimes ☐ Never ☐ N/A ☐

(14) Do you feel that anyone appreciates you as a caregiver?

Always ☐ Often ☐ Sometimes ☐ Never ☐ N/A ☐

(15) Does caregiving have a negative effect on your emotional well-being?

Always ☐ Often ☐ Sometimes ☐ Never ☐

Is there anything else you would like to tell us?

The University of Hertfordshire, Health and Human Sciences ECDA. Protocol number: aNMSCC/12/12/3/A.

Appendix 4: The Diary

Introductory Page

How to fill in your diary

Thank-you for agreeing to take part in this study. Here are some points to consider when completing the diary.

I am interested in any social contact that you have at any time and I would like you to log all of your social interactions for a 2 week period.

However, if the contact particularly helps or maybe hinders you in your caring role then it would be very useful if you could write something more about this.

It would be useful to know if it was helpful because of any of the following:

- The friendship or kindness
- The information or advice you received and what that might be
- The emotional support you received and what that might be
- The practical or financial support you may have received and what that might be

It would be useful to know if it was unhelpful or a hindrance because of any of the following:

- It resulted in a disagreement between yourself and the contact
- It left you feeling upset and angry
- The lack of information or advice you received
- The lack of emotional support
- The lack of practical support or financial help and what was not forthcoming.
- These lists are not exhaustive you may have other reasons that you want to add.

You may wish to complete it through the day after each social contact or you may decide to do it in the evening. It may be that some days there are more contacts than others. It may be that some days you had no contact. Either way it does not matter.

Please do not worry about your best handwriting your spelling or grammar but just try to write as clearly as you can with a pen.

Appendix 4: The Diary

Each contact you have can be logged in the boxes provided. There is then a space for you to write how this contact impacted on you as a carer and how it helped or hindered you in your role. Please note contact names will be changed by the researcher to protect anonymity.

If you find you have missed some days, please do not worry and please do not give up. Just start again on the next day you can.

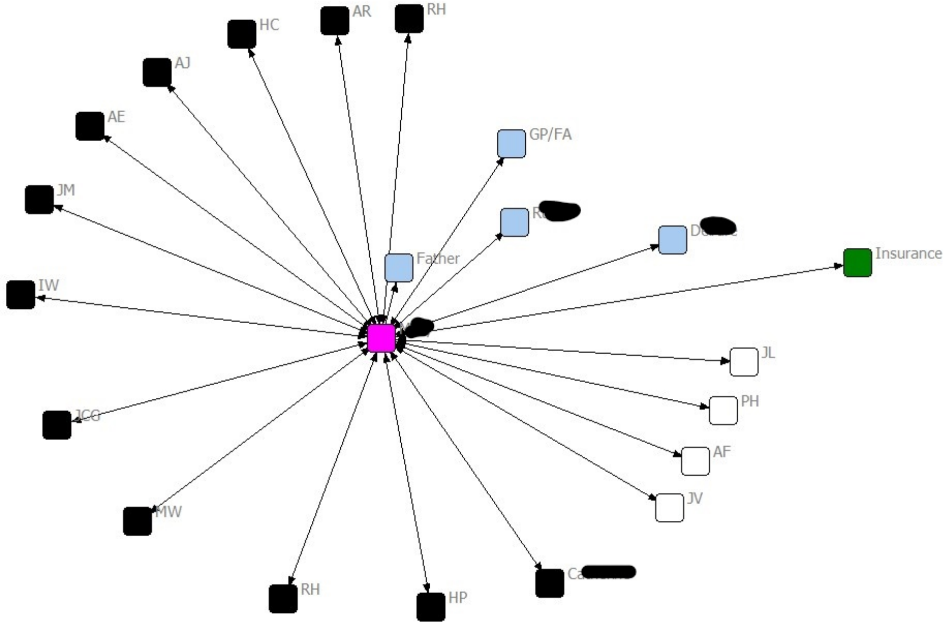
EXAMPLES OF MEANS OF CONTACT	EXAMPLES OF RELATIONSHIPS/ROLE
In Person Telephone By Post By email Text Social media	Family (Mother, Father, Brother, Sister, Son, Daughter etc.) Friend Qualified Health/ Social Work Professional Unqualified Health Worker Volunteer Neighbour Colleague Acquaintance Stranger

Appendix 4: The Diary

Date	Time	Name	Relationship/ Role	Place	Means of Contact	Comments

Appendix 5: The Sociogram

Sociogram of the Diary Data: Monica



Appendix 6: Ethical Approval

UNIVERSITY OF HERTFORDSHIRE

ETHICS COMMITTEE for NURSING, MIDWIFERY, SOCIAL WORK, CRIMINAL JUSTICE AND COUNSELLING

<u>FEEDBACK</u>

Applicant	Jane Say
Study	Exploring Carers' Social Networks and their impact on Caring
Reference Number:	NMSCC/12/12/3/A
Date of REC	6 December 2012

Overall comments.

Thank you for resubmitting this very interesting research project.

You have met our requirements and we are happy to approve the application.

Ethics Committee for NMSCC decision:

Approved X
Your study is registered with approval number: NMSCC/12/12/3/A

Minor amendments required - subject to Chair's action ☐

Major amendments required - resubmission to REC

Not approved ☐

K Goode

Kim Goode
Chair of the Ethics Committee for Nursing, Midwifery, Social Work, Criminal Justice and Counselling
Dated: 9 April 2013

Appendix 7: Participant Information Sheet

Caring for those with Parkinson's: The Impact of Social Networks on the Caring Role

Researcher:
Jane Say
Contact details:
Tel: 01707285941
Email j.say@herts.ac.uk

University of Hertfordshire UH

You are being invited to take part in a research study.
To begin it is important that you understand what the research is about and what it will involve. Please take some time to read this information and please talk to others about the study if that will help. Please contact Jane Say if you need anything clarified or require further information.

What is the study about?
As a carer you may have a network of people including friends, family, acquaintances, health professionals and others who support and aid you in your caring role. These social networks may be a real help in your caring role, however, sometimes they might not be so positive. This study wants to find out about carers' social networks, how carers use them and what aspects of their social networks might help or hinder carers in their role.
Understanding how carers use their social networks in their caring role could help those providing and delivering support to re-design and shape their services so that they are more effective.

Why am I being asked to take part?
We are inviting carers of people with Parkinson's disease, who are aged 18 years and over to take part.

Do I have to be part of this study?
Your participation is voluntary. If you decide to take part you will be asked to sign a consent form. You are free to withdraw from the study at any time, without giving a reason, and any data you have provided will be destroyed. A decision to withdraw will not affect your health or social care.

What will the study involve if I do agree to be part of it?
Initially you will be asked some questions about yourself and how you find your caring role. These questions should take no more than 15 minutes to complete. You will then be asked if you would like to undertake 2 interviews (of about 45 minutes to 1 hour each) and keep a diary for 2 weeks. This is to obtain more in-depth information on your social networks. The interviews will take place in the most convenient location for you such as your home. You will be asked permission to tape record the interviews. In the first interview you will be asked questions about the people that make up your social network. Keeping the diary will

Appendix 7: Participant Information Sheet

involve you making notes of your interactions with different people in your caring role. In the second interview (based on the information from the first interview and the diary) you will be asked to talk more about the people in your social networks and their impact on your caring role. There are no right or wrong answers; the focus is on your life as a carer.

Are there are disadvantages or risks in taking part?
It is not anticipated that there will be any risk in taking part. There are no disadvantages except that your time will be needed to complete the different parts of the study. If at any time you have a problem or concern with the study then please contact Jane Say or her supervisors (contact details are at the end of this booklet).

What are the benefits of being involved with this?
There is unlikely to be any personal benefit from being in the study and you will not be paid for taking part. Although you would be reimbursed for reasonable travel expenses if this was necessary. However it is hoped that your participation will help those that provide and deliver services understand carers' networks and the nature of support in those networks.

Will information about me or my family be kept confidential?
Yes. All information about your participation will be kept confidential. Any information that you share will be made anonymous so that you cannot be personally identified. All data storage and use will comply with the Data Protection Act (1998) and data will be securely held for 5 years from the end of the study.

What will happen to the results of the study?
The findings will form part of a Doctoral thesis that will be submitted to the University of Hertfordshire for examination. Some of the findings may be published in academic and professional journals and presented at academic conferences. If you wish a summary of the findings can be sent to you. Please let Jane Say know.

Who has reviewed the study?
The University of Hertfordshire, Health and Human Sciences ECDA.Protocol number: aNMSCC/12/12/3/A.

What do I need to do to get involved?
If you decide you wish to take part in the study please complete the form at the end of this leaflet and return it in the pre-paid envelope. You will then be contacted to answer any questions you may have and to begin the study.

Main researcher and contact for further information
Jane Say
Pre-Registration Nursing Lead, School of Health and Social Work, University of Hertfordshire, Hatfield, Herts AL10 9AB
Tel: 0170728-5941 email: j.say@herts.ac.uk

If you need further information or have any concerns about the way in which the study has been conducted please contact the Research Supervisors.
Dr Angela Dickinson
Senior Research Fellow
Tel: 01707 285993 e-mail:a.m.dickinson@herts.ac.uk

Dr Charles Simpson
Research Fellow:
Tel: 01707 285927 e-mail c.m.simpson@herts.ac.uk
Both are based at:
Centre for Research in Primary and Community Care (CRIPACC), University of Hertfordshire, Hatfield, Herts AL10 9AB

Thank you for taking the time to read this and for considering whether to take part.

If you do take part you will be given a copy of this information booklet and a signed consent form to keep.

Please feel free to share this information with family and friends.

Appendix 8: Consent Form

CONSENT FORM FOR RESEARCH STUDY

TITLE OF STUDY:

Caring for those with Parkinson’s: The Impact of Social Networks on the Caring Role

Participant Identification Number for this Study…………………………………..

Name of Researcher: Jane Say

Contact Details : School of Health and Social Work
University of Hertfordshire
Hatfield
Herts AL10 9AB
Telephone 0170728-5941/ Email: j.say@herts.ac.uk

Please place initials in the box if you agree

1. I agree that I have read and understood the participant information sheet ☐
2. I have had a chance to consider the information provided and have been given the opportunity to ask questions. Any questions I have asked have been satisfactorily answered ☐
3. I am willing to volunteer for this study and I understand that I can withdraw from the study at any time without giving any reason and without there being any negative consequences. ☐
   .
4. I understand that this consent form and any data collected will be stored securely at the University of Hertfordshire in accordance with the Data Protection Act (1998). It will be destroyed 5 years after the end of the study. ☐
5. I understand that I will be asked to talk about my social networks and my caring role and I agree that the interview can be tape recorded. ☐
6. I agree that any words I may say during the interview can be used, anonymously as quotations, in the presentation of the research. ☐
7. I understand that you will only tell other people my name/address or what I say/do if you think someone in this household is in danger. ☐
8. I agree to take part in this study ☐

Participant name	Date	Signature
…………………………	………….	……………………………..
Researcher Name	Date	Signature
…………………………	………….	…………………………….

The University of Hertfordshire, Health and Human Sciences ECDA. Protocol number: aNMSCC/12/12/3/A.

Appendix 9: Parkinson's UK Support Confirmation

On 20 Aug 2013, at 10:32, "Hannah Churchill" <hchurchill@parkinsons.org.uk> wrote:

Dear Jane

Many thanks for your email and for send over all of the required documents, it sounds like a very interesting project. I'm more than happy to assist you in finding participants for your study.

I'd suggest the first step would be for me to send the detail of your study out to our research support network (a group of people who are interested in getting involved in research) in London and Eastern England.

In the form you completed you said you were looking for participants based in Hertfordshire and North London, it may be difficult to find 60 participants in that specific area. Would you be able to spread your recruitment further afield? If not, it may be worthwhile approaching some of the local groups in your area, I can put you in touch with our 'Branch and volunteer support officer' based in the region, who may be able to suggest groups that are interested in research.

I'd also be happy to add the study to the ' Taking part in studies' page of our website and once our online forum is up and running you may be interested to post on our forum.

Please do let me know, I'm happy to send the details to our network at the end of the week.

Best wishes

Hanna

Appendix 10: Key Stages of the Analytical Process

1.Initial Coding

Coding Example

In the example (see Table A1), using the network data at the interview I was exploring Henry's family and their support particularly his daughter and his sister-in-law. Towards the end of this excerpt, the changing support from family/friends was introduced by the carer. The dynamics of family life and the temporal changes of the network became apparent. For each case, early coding and familiarisation helped to build several themes and subthemes that with *a priori* concepts became part of the thematic frameworks.

2. Developing the Initial Thematic Frameworks

Several key themes were identified with subthemes within them. These were used to 'interrogate the data for each case.
The initial thematic frameworks were refined/evolved as the early data analysis continued. See Table A2.

3. Applying the Framework/Indexing and Sorting

Returning to the data within NVivo™ 11allowed for the framework to be applied directly to the data. See Table A3

4. Data Summary and Display: Abstract and Interpretation

A framework matrix was used for each case in a tabulated form. The example shown is from Caroline (case 14). As I worked on the frameworks I added in direct quotes where these really captured the sense of the carer/carers' experience. These tables were used to refine, distil, and abstract the coded data and to compare it across different cases. The comments were useful to draw together ideas and acted as memos in parts. They were also used to highlight links to other cases. Notes, highlights, and underscores facilitated interpretation. This helped to refine the themes, subthemes, and key concepts.

See Table A4 and memo to illustrate interpretation.

5. The Final Analysis

The conclusion of the abstraction of the data was three separate tables used in chapters 5, 6 and 7 that identified the following: (See Table A5 as presented in chapter 6)

- The Over-Arching Concept
- Theme
- Sub-theme and Key elements

Appendix 10: Key Stages of the Analytical Process

Table A1: Initial Coding

Henry case 13

	Initial Codes
Henry: [Name] my sister in law, [wife's] sister… JS: Yeah…yeah, yeah sorry yeah that, so you would talk to [sister in law] about your caring role…? Henry: Yes I would, err she would talk to me (laughs) really… JS (laughs) Right ok, you have no option… Henry: Yes…And I would also talk to [Daughter], I think… JS: Oh right, let me add [Daughter] in…umm and then you've got [name friend] your friend… HC-13: Yes… JS: Yeah is [name friend] the one, were you going, I think when I rang one night, were you going to the cinema with [name friend], you go out with him regularly…yeah, yeah, yeah…? HC-13: Yes that's right, we try to get out… JS: Yeah and then the other questions was umm…was about erm…who can you count on to provide care, to support, who can you count on to support you providing care…? And you've got [sister in law] there again, you've got [daughter] and you've got [Henry's sister name], which is your sister… HC-13: My sister yes… JS: Is she local, to you…? Henry: No she's also in [X County] umm… JS: I think you said it's a bit of a coincidence… Henry: Yes, she's in the next door village to [sister in law] , she's about to move but she had her husband died umm, in the summer after a short illness and so forth and err…children who, her eldest son, who was in X has now moved to X county and [sister] is going to move too.	This was early in the interview as we discussed the name generator data. **Code**: Female family who support H in caring role. **Code**: Sister-in-law dominant in caring support **Code**: Talks caring/has social contact with old friend **Memo**: 'Old friends' longevity of relationship noted **Code**: Female family who support H in caring role. **Memo**: 'Dominance of females' in support for caring (despite two sons, sister, sister-in-law and daughter are main support). **Code**: Changing circumstances of sister-potential effects for H and his contact/support

Appendix 10: Key Stages of the Analytical Process

Table A2: The Initial Thematic Framework

Theme	Notes
1 Personal details (current) 1.1 Demographic/relationship to cared-for person/ Personal Biography 1.2 Living arrangements 1.3 Employment/educational activity 1.4 Health 1.5 Other	Sections 1-3 were used to ascertain the background and biography of the carers. Chapter 4 presents some of this data
2 COPE Index 2.1 Negative Impact Scale 2.2 Positive Value Scale 2.3 The Quality of Support Scale 2.4 Other	Examining this highlighted those who were finding difficulties with their role.
3 The Network Data 3.1 Name Generator /Diary Interactions/ Alters Listed 3.2 Diary Days kept 3.3 Alters-Total numbers/Classification 3.4 Means of contact 3.5 Other	This section was used early in the analysis as a means of orientating to the different alters that the carer interacted with. This underpinned sections 4, 5 and 6-see below. Overtime this data was subsumed into these other sections. This data was used to determine the typologies.

Appendix 10: Key Stages of the Analytical Process

Table A2: continued: The Initial Thematic Framework

Theme	Notes
4. The Personal Community-The Role of Family, Friends and Neighbours 4.1 Key alters, roles, relationships 4.2 Carer support/types 4.3 Relationship dynamics: Bonding Social capital (intergenerational, reciprocity, negotiation, ambivalence, antagonism, mutuality) 4.4 Gender 4.5 Temporal Changes	This was developed using a priori structural elements of the network (as were sections 5 and 6). This developed into the data presented in chapter 5.
5 The Role of Third Sector Organisations 5.1 Entry In and Out 5.2 Accessing resources-Bridging Social Capital 5.3 Utility and Support for Chronic Illness Work 5.4 Outcomes for the Carer	This developed into the data presented in chapter 6.
6 The Role of Health and Social Care 6.1 Knowledge about 6.2 Accessing resources-Linking Social Capital 6.3 HP Relationships	This expanded during the analysis and developed into the data presented in chapter 7
7 The Network in Action 7.1 Access and barriers 7.2 Communication 7.3 Changes over time 7.4 Shaping the network: Navigation and Negotiation 7.5 Other	This was originally a separate theme and was used to capture the movement and fluidity of the network. Overtime the ‘network in action’ was subsumed into the sections 4. 5 and 6.

Appendix 10: Key Stages of the Analytical Process

Table A3: Applying the Framework: Indexing and Sorting

Cilla case 2

	Applying the Framework Index
..the GP then made the arrangements…like for early part of this year…The memory doctor Consultant came here…assessed. H and thought he was pretty good…good on that but he was saying it needs to be increased…and it's taken a long time…and the memory err side…umm I mean I can always speak with [ISW] on this as well…but the memory side they never linked up properly…err they used to…they'd phone up…have you got the new medication…I said no…well you'd better get onto the GP…so I said…don't tell me what I've got to do…you are authorising the change of medication…you should be dealing with it and letting me know…it's not down to me…and in the end the GP phoned me and had a letter from the Consultant…so it went to the correct circle…and err we've now got the medication and obviously as you know how they supply the medication…	6.2 Accessing (health) resources 5.2 Accessing resources (information via PUK, ISW). 7.4 Carer negotiation/navigation 6.3 Health professional relationship

Appendix 10: Key Stages of the Analytical Process

Table A4: Abstraction and Interpretation

5 The Role of Third Sector Organisations- ..(*wonderful support groups.. wonderful friendships…people we can't wait to spend time with because there's so much happiness* (Case 1)					
Case	5.1 Entry In and Out Group attributes and dynamics QUERY Bridging to Bonding social capital	5.2 (Using contacts) Accessing/Sharing (or Available) resources- (Pathways to Bridges) Bridging Social Capital	5.3 Utility and Support for Chronic Illness Work	5.4 Outcomes for the Carer	Comments
Case 14 Female Married COPE NA Caring for her father	On entry father met old colleague at PUK 10. *So when, when he actually did finally go to Parkinson's and he walked in the door and he, he sees her and recognised her so I think that cushioned it a bit more for him yeah…* PUK- 2 groups –that have alternative weekly meetings	Met ex-colleague of Father- and also the pharmacist assistant that she knows –is in the group because her husband has PD. Mrs C has formed a good friendship with John –another PD sufferer. ..20 *he's just like buffer*, you can talk to him and *he'll, he listens and he talks and that and he gets on well with my Dad and all and they have a little laugh and joke together…* *21 Is he a carer, [name]...? Yeah*	The opening up of a different social world has been important to Mrs C- Discussing the groups and the social aspects that are separate to the disease JS 91 *…would you try and go most weeks…?* 92 *Yeah, yeah because I enjoy going, I enjoy talking to everybody, they've become friends to me as well, you know, we have a game of scrabble or…dominoes, and that, sit and chat, and it's not chatting about Parkinson's, its chatting about everything, life, some of them have had such interesting lives…*	Note Initial comments on PUK – right at the start of the interview. *2. 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 so… there's always somebody… You can't ask for anything more than that can you…?* Social, friendship, physical activity for both. Note- Mutuality-Father encouraged C to try the bowls	Also–registered for dial a ride –helps with father's transport between his home and daughter's Note some negotiation between Father and carer about the PUK group and the carer joining –a sense that both may need separate spaces and time a apart- see case 3. Case 12, Making sense of the illness through talking and sharing experiences. Helps to recognise 'good days' and bad days'

Appendix 10: Key Stages of the Analytical Process

Data Interpretation

The Carer as a Network Bridge and Network Co-ordinator

In examining the data, the themes that emerged from the matrix were generated from the cases, across cases and in parts across the three key overarching conceptual categories. The carer as a network bridge, broker/co-ordinator and go between was one such theme. This was considered in relation to the informal and formal aspects of the network, the dynamics of the network and the carers' role in the orchestration of the network. Key elements within this were negotiation and navigation, although there were also temporal considerations, life course perspectives and resources (e.g., finances, personal contacts) that all impacted on this. In different aspects of the network the carers' role in this respect varied.

In considering this a memo was written to capture this role and the subtle differences in that role across the network

Summarising the Data (A Memo)

Defining the Carer as a Network Bridge, Coordinator and Go Between

> *Bridges, brokers and boundary spanners facilitate transactions and the flow of information between people or groups* (Long et al. 2013)

Key Aspects

Navigation and negotiation/ Conduit between different network members/ The 'work' of this across the network/Carer agency

Informal network

Within the informal network, the carer negotiates with kin and close friends/others to garner support. This is done in the context of their family/ friendships/ other informal relationships. The carer is cognisant of the current situation that she/he finds themselves in, the needs of the care-recipient and the availability/propensity for support that might be forthcoming. Cases that appeared adept at this (case 4, case 13, case 9, case 15). For Monica, the time to ask and negotiate with her brother was right – this seemed key for the request for more help.
Monica: [Transition/trajectory/juggling] *I think we're going into <u>a different phase</u> at the moment erm…and it's <u>about the balance</u>… 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,* [negotiation] *Jack a favour would you be able to come and err, stay and he said, yes… but I think it <u>will do them…you know good</u>* [life-course-interdependencies], …..[contexts] *<u>as my Father is deteriorating I would hate it that he hadn't seen him before he died…</u>*

Henry, Elizabeth (*<u>Who can do what for you</u>*), Gary, Margaret were discerning/adept at identifying, negotiating and coordinating friends who could help with instrumental/respite support.

Appendix 10: Key Stages of the Analytical Process

Third Sector

Two aspects to consider here- the bridging to the TSOs to make new friends, access more resources (this was often a joint effort, with the carer-recipient e.g. Adam and wife), although for some carers this was a very key part of their role in this respect (Gary, Denis, Carly, Debbie, Cilla, Margaret, Maureen).

On entry there was evidence that the carer became a 'go to' person or conduit in signposting, information giving and extending the networks of others (e.g. Carly and Mary's chance meeting and the introduction of Carly to the dance group. Then Carly introducing me to the dance group). Other members of these groups were described in this way in how they operated across the network.

Health and Social Care

This role was particularly evident in carers' who were managing complex medical needs. The diary is particularly useful at identifying this aspect in real time.

Carly, trying to organise respite care through carer hub and other agencies (in this case example the carer was working across agencies and drawing on own resources-after one agency was unreliable-- *so I then had to ring around people I knew…that someone who worked for the NHS and somebody else, umm who had contacts with people in medical err facilities and through her at 8pm at night I finally got an agency who said don't worry we can do it…*).

Elizabeth, describing medicines management (*the timing of medication and availability of drugs is my biggest single worry*) and the work of co-ordinating multiple health professionals and appointments (mainly via private care).

Dawit's extensive diary entry on trying to source a particular dosage of tablet across his local area, Conversations, discussions, information sharing all evident with a number of health professionals, pharmacies and the GP.

In these cases, accessing what was needed was potentially difficult, and could be because of a number of reasons e.g. individuals/organisations involved were unreliable or the scenario was complex. or the volume of HP involvement was extensive and disparate in parts.

Refer to Twigg and Aitken (1994) *Carer as co-worker.* Expert patient/carer work. Asabo (2017) work on negotiation in the health setting

The negotiations caregivers participated in and the uncertainty they experienced shed new light on the complexity of their role,and the discrepancy between practice and ideals in healthcare policy regarding collaboration of care.

Deviant Cases: Those where this role was less evident or not evident at all, were at a different point in the care trajectory with either the care-recipient not as dependent on the carer or other informal carers were co-ordinating aspects of care more than the carer (e.g. Lenny, step-daughters involvement)

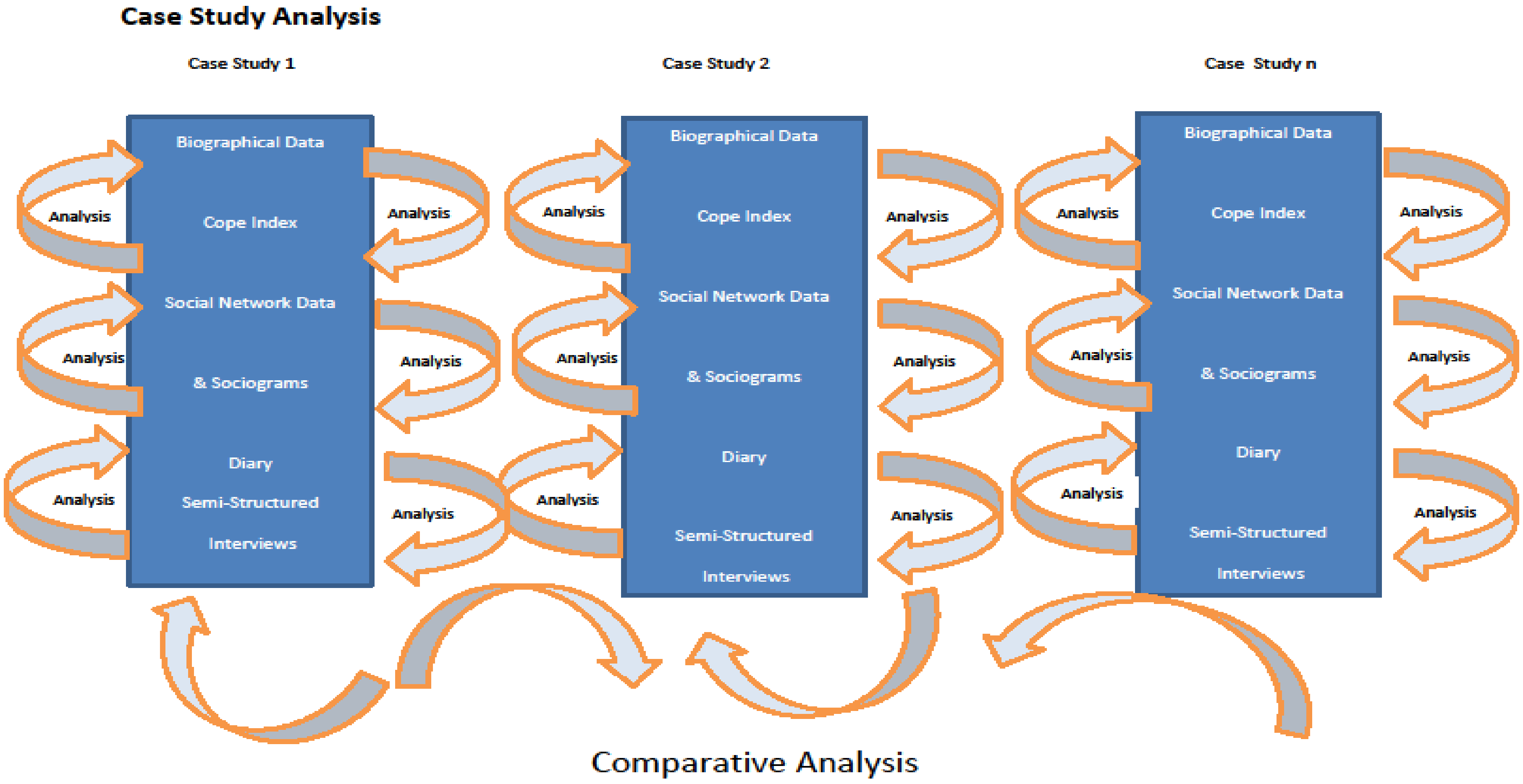
Appendix 10: Key Stages of the Analytical Process

Table A5: The Final Analysis

Third Sector Organisations: Concepts, Themes and Subthemes

Over-Arching Concept	Theme	Sub-theme	Key Elements
Third Sector Organisations (TSOs): Bridging and Connecting *A whole new world has opened up to us*	The Range of TSOs Accessed Building Bridges to Shape the Network	Group Entry	<u>Intrinsic Factors</u> Fear and stigma Sociability Carer and care-recipient 'needs' <u>Extrinsic Factors</u> Group attributes (bonds and connections) Locality and accessibility Helplines and on-line presence Introductions-opening doors
	A Lifeline The Network in Action: Accessing and Utilising Resources	Carer Well-being	Cognitive and physical well-being • Events, classes, outings and holidays • Respite and restoration • Personal and vicarious enjoyment Self-esteem • Utilising and developing skills • Social Companionship: *Wonderful support groups...wonderful friendships so much happiness*
		Support with Illness Work	Developing knowledge and skills • ISW and 'Go to' people (network bridges) • Health Professional Contact • The Group: *Everybody was sharing and everybody was quite willing to listen to everybody else share*

Appendix 11: A Diagrammatic Representation of the Case Study Analysis



Appendix 12: The Participants

The Participants

Carly: Carly is 62-year-old female married to Robert (her second husband) who has had Parkinson's for over 12 years. She spends 133h per week caring i.e., full time, all day, and 7 days/week. She lives with her spouse and is retired. Her health is fair, and she had previously received counselling to help her deal with her caring role. As an immigrant, she maintained contact with her children and friends overseas by Skype/email. She appeared an outgoing person whose social network was dominated by friends. Her involvement with PUK was extensive and she had also been involved with a carers' hub. Carly appeared able to navigate and readily construct a care network around her and her husband. She had formed a good relationship with their GP and appeared always vigilant to seek new opportunities to find help and support. She discussed her advocacy role in promoting carers' issues and being involved in the education and training of health professionals. From the COPE index caring appeared to be having a negative effect.

Cilla: Cilla is a 74-year-old female married to Charlie who has had Parkinson's for over 23 years. She spends more than 100h per week caring i.e., full time, all day, and 7 days/week. Cilla lives with her spouse and is retired. Her health is fair. The couple do not have children. Their niece is their next of kin but lives over an hour away. An old friend (known over 50 years) was discussed as being an important source of support. Cilia alluded to several arguments with friends and family. There also was conflict with health professionals. Cilla has previously been involved in voluntary hobby groups and saw PUK as a social outlet that could offer advice, information and some practical support. The daily 'Club' (organised through a local charity organisation) that Charlie attended was an important time for respite for Cilla. She, too, had some involvement and attended lunches/activities and organised day trips. No issues were raised on the COPE index.

Mary: Mary at 47 was the youngest carer. She cared for her Mother who has had Parkinson's for over 7 years. She spends 35+ hours per week. Mary lives alone but sees her Mother 5 days per week. Her health is poor. An only child, she was estranged from her Father (her parents divorced when she was a child) and the wider family, Mary had the smallest network with a limited number of friends. Her scores across the COPE Index were the most extreme. Mary appeared to be dealing with anxiety about her Mother's condition and feared for the future. Her relationship with her wider family was antagonistic and she felt they had given her and her Mother little support over the years. Mary had encouraged her Mother's involvement in PUK. Contacts aided their involvement. This had become an important component of their social circle and support in to dealing with the disease.

Elizabeth: Elizabeth is a 67-year-old female married to M. She is his second wife and has three stepchildren. Her relationship has been very mixed with these children. She had been close to the oldest daughter, but now this relationship has deteriorated. M has had Parkinson's for over 6 years. She spends over 100h per week caring. Elizabeth lives with her spouse and finished work several years ago when her husband was ill with cancer. Her health is very good and there were no scores above/below threshold on the COPE index. The couple are wealthy and have extensive private healthcare. She has several friends. She is especially close to her brother who is now being paid to provide care to her husband. She also talked about ‘being frightened’ and ‘not able to cope’. She had felt under ‘house arrest’ as M’s condition worsened, and she felt she couldn’t leave him alone. PUK and especially the singing group which was a joint activity that the couple enjoyed.

Julia: Julia is a 75-year-old female married to B. B was diagnosed with Parkinson’s Disease four years go although there were symptoms sometime prior to diagnosis. Julia spends 24h per week caring. She lives with her spouse and her health is fair. The couple are childless but have a nephew who lives over an hour away and is their next of kin. An old friend who B knew from his working life is also a key person who provides support. They have been active in local community groups for many years. Julia maintains contact with her old work colleagues, although she was finding that she did not want to socialise and leave B alone in the evening. The COPE score was low in terms of quality of support. They joined PUK groups a year ago. They liked the homophily of the PD group. They like the talks from the neurologist and other health professionals. They have gained access to two dance groups and a singing group from this. The local carers group have also provided equipment, but they are nervous to join since other people with different conditions will be there …’people with drug problem, alcohol problem… so I’ll be nervous because they can be aggressive…’Julia did not wish to complete the diary personally, so the diary data was collected by phone at the mid-point and then at interview covering an 18-day period. The diary had only seven contacts which were all face to face except for one which was their nephew on the telephone.

Harriet: Harriet is a 67-year-old female married to R who has been diagnosed with Parkinson’s 18 months ago. She spends 2 h per week caring. Her health is fair she has been diagnosed with multiple sclerosis but has relatively mild symptoms. She has always been involved in a lot of community/hobby groups and has a wide circle of friends. The couple have only just started to attend PUK meetings. Harriet seemed unsure about their involvement- ‘it’s early days yet’ and seemed to be unsure about how the disease might progress and what the future may hold. Her own illness meant that she had contact with a specialist neurological unit and had encouraged her husband to contact them. At the time of interview Harriet felt that they did not need much support to manage the PD.

Margaret: MS is a 74-year-old female married to J who has had Parkinson’s for over 10 years. She spends 70h per week caring. MS lives with her spouse and is retired. Her health is fair. Margaret and her husband are well established in the local area. They know their neighbours who provide some respite by taking J out. Margaret’s daughters live close by. All daughters support their parents,but one offers instrumental support and is viewed by Margaret as the most helpful. Margaret’s diary demonstrated the local support she received from family, friends, and neighbours.

Susan: Susan is a 68-year-old female married to K who has had Parkinson’s for 4 years. She spends 56h per week caring. Susan lives with her spouse and is semi-retired. Her health was initially indicated as good, however at the interview she described panic attacks and anxiety. She did comment on the initial recruitment documents, ‘Being a carer to my husband who has Parkinson’s has taken over my life.

Appendix 12: The Participants

It is difficult separating being a wife and carer. It's often a lonely existence.' For the COPE index, the negative impact had a score of over 16 indicating that caring is having an effect. Susan's sons live some distance away. They maintain contact via Skype. Her primary support is her sister and their relationship had become increasingly close. *'*She's my sister, she's a good friend… we're very close*.'* K was in receipt of domiciliary care and the couple had increased the number of days the carer attended in a privately paid arrangement.

Monica: Monica is a 62-year-old semi-retired GP caring for her 97-year-old Father. She is a widow and has no children. Her brother lives over 100 miles away. Her health is good. She is the main carer and has recently moved in with her father since she was spending increasing amounts of time with him. She has been a serial carer, supporting her father to care for her Mother over a 10 year period before her death. Following this Monica's husband also developed PD and died only a year ago. She has many professional and family contacts in healthcare who she uses to access support, advice, and contacts for medical referrals. She has been a member of Parkinson's UK and particularly one of the dance classes that she attended with her husband also. She is finding the time needed to be with her father is increasing and he is becoming very frail. She has had recent negotiations with her brother for him to become more involved in their father's care.

Adam: Adam is 72-year-old male married to J who has had Parkinson's for 8.5 years. He spends 10h per week caring. AR lives with his spouse and is retired. His health is good. Adam completed an electronic version of the diary, and the data was extensive. The diary was kept for 22 days and involved 127 interactions with over 91 alters. However not all interactions were related to the caring role. These interactions were nearly all through his role that he had at his local church. For Adam, his wife and their family, church was integral to their lives, and it was evident that affective and instrumental support would be available if they needed it. His wife had become very active in the PUK group, and he had developed a close friendship with two other male carers who he talked to regularly. He utilised his technical skills to support the group's activities. There had been some conflict and tension with a consultant neurologist and after considering feedback about other Consultants at the PUK meetings decided to change

Lenny: Lenny is a 62-year-old female married to Eva (Lenny is her second husband). Eva has had Parkinson's for 6 years. He spends 168h per week caring. Lenny lives with his spouse and is retired. His health is good. He has two stepchildren with whom he has a good relationship with. Although living over one hour travelling distance away, they did have regular visits (once or twice per month) and telephone contact. They were pro-active in discussing their mother's care and he viewed them not only as family but also friends. Lenny was a quiet reserved man with few close friends, although he had contact with siblings overseas. For the COPE scale the quality of support score was low at 3. This is because several responses were ticked as NA which scores 1. However, it does demonstrate the small network of contacts that are available to Lenny for support. Although covering a 26-day period from the first to the last entry, only 3 entries were made. He did enjoy the activities and knowledge he gained from attending PUK meetings with his wife.

Appendix 12: The Participants

Henry: Henry is 66 years old and is caring for his wife (Sandra) for the last 16 years. His health is good. They have three adult children, and one son still lives at home. Henry is now retired and was semi-retired for six years because of his wife's deteriorating health. They are well established members of the Parkinson's UK group and have a circle of friends that they socialise with through that group. They also attend a PD dance class in the summer. Sandra attends a day centre one day per week. Henry's daughter, sister and sister-in-law are key in supporting Henry. His son at home will look after his mother occasionally to give Henry respite time to go out. He manages a very complex medicine regimen (including an infusion pump) with no support from the community nurses.

Dawit: Dawit was the youngest male carer at 57 years old. He has been caring for nine years but had given up work a year ago to care for his wife (Zara) full time. He was now caring for 168h per week. From the COPE index, the negative impact score was high at 15 and the positive score low. His wife condition had deteriorated significantly, and she was on a complex medicine regime requiring specialist supplies and District Nurse support. He had a son at University and other caring responsibilities. Their first son had been born with a serious physical and learning disability and had died after a long period just before Z was diagnosed with PD. Dawit was a quiet reserved man who did not want to socialise. He had a range of family and friends who offered support but at times the cultural demands and expectations from the family and others were overwhelming and stressful ('to be honest I'm not short of people who volunteer, it is me who does not want it). PUK he found useful for information and he used the time when Z attended to catch up on chores, shopping etc. It was striking how organised and co-ordinated Dawit was and needed to be in the role.

Caroline: Caroline is 57 years old and married. Her health is fair. She has been caring for her widowed Father for the last 2 years since he was diagnosed with PD. She is married with four sons (three are over 18 years and one is still at school). All live with Caroline and her husband. Caroline relies on one of her adult sons not her husband for emotional support. Although no friends were listed in her network, her cousin is classed as a friend and is very supportive to Caroline in her caring role. She is unemployed and she misses her work and the independence that her wage gave her. However, she is also relieved since caring for her father has required a lot of hospital and GP visits which would have been difficult whilst working. She has become more involved in the Parkinson's UK group and is really enjoying the activities and outings. Interestingly, she has made friends with one PD sufferer who is also a carer for his wife. She finds that she can discuss PD with him, and he is very informative

Debbie: Debbie is a 72 year-old lives with her husband, Matt and has been caring for 15 years. She cares for 168h per week. She has three children and her youngest daughter, her husband and small grandchild along with another adult grandchild all live with Debbie. She still enjoys looking after her youngest grandson when she can. From the COPE index, the negative impact score was high at 15 and the positive score was low indicating that Debbie is finding the care role more difficult. Her husband's condition was deteriorating and cognitively he was having difficulties with memory loss. An Admiral nurse had visited the couple. During the period of the data collection, M was taken ill and hospitalised. The diary data charted much of this period. The family were supportive and involved throughout this time. Although previously it had been difficult to garner some regular respite support from her children. A support package was started post discharge for M and was in place at the interview. Debbie recognised that this needed to continue and was waiting for an assessment for this.

Gerald: The family are close and central to support. Two daughters live in proximity that aids regular help and contact. A brother-in-law is also supportive and visits regularly with his wife's sisters and other brother also in regular contact. Gerald uses Skype-but his wife doesn't like it. The church is also central to their network ('church family'-diary comment) and he helps with a church café in the week. It helps him to be a part of the wider community because of this. Their experiences of the healthcare system contrasted between the care they received when living in the south-west which was very facilitative compared to the specialist team they were referred to on return to [name of town]. Medicines management features highly. The role of the Consultant and the pharmacist are particularly highlighted in this. They have a referral to a specialist OT and the GP has assisted access to specialist resources. Reciprocity and mutuality are also evident particularly with the family. Gerald gives his daughter, who has a severe physical disability occasional help to wash her hair. Looking after this daughter throughout her life has also meant that he has provided a lot of intense care over many years.

Tom: Tom is a 71-year-old male married to S who has had Parkinson's for 33 years. He cares for 165 hours per week. He lives with his spouse and is retired. His health is good. From the COPE index, the negative impact score was high at 15 and may indicate that TJ is finding the care role more difficult. The social support scores would also indicate that he does not have the support required. He has a daughter who lives at home; however, she was identified as being unhelpful in terms of his caring role. The discussion about his daughter involvement indicated a difficult relationship. Their Grandson lives with them and there is a close relationship with him since the couple have helped to bring him up. Tom wanted more weekly respite than he is currently received. His request appeared modest, but he appeared frustrated with the system as he discussed his current position and his discussions with professionals to get access.

Denis: Denis is a 79-year-old male married to P who has had Parkinson's for 13 years. He could not state how many hours per week he is caring but from the interview it appeared full time. Denis lives with his spouse, and he is retired. His health is very good. On the COPE score for quality of support it was low <7 and therefore may indicate that access to support is limited. Denis added some extra notes to his diary entry. He noted that from filling in the diary that 'little of the social contact had anything to do with or resulted from caring.' Denis emphasised that the survey cannot show 'what social contact is lost because of Parkinson's.' The demands of caring and need to limit time away from P means that Denis does not do as much as previously and as such this 'limits my opportunities to socialise.' He also noted that [people].. 'sympathise' with our plight but that does not alter our lives in any way.' Denis was involved very actively in PUK (as Chair and on the committee) but now just attends the meeting. Although they had garnered information, Denis appeared to like the more social side of the organisation. Enjoyed organising and managing the group. The couple accessed a private neurologist for P's treatment and like the convenience and access.

Appendix 12: The Participants

Maureen: Maureen is an outgoing sprightly 80-year-old who still drives, which is important since travel from the village would be difficult. She lives with her husband who has had Parkinson's for 5-6 years. She cares for 84h per week. This network is predominantly locally based and involves family, friends, church and PUK. Maureen has 2 daughters, one who lives close by, and she has a good relationship with them. They are busy and she doesn't want to ask them to care for C. She has several close friends in the village who she would call on in an emergency. She is active at the WI and in the church. She has lived in the village for all her married life and therefore has a lot of friends and contacts. In terms of the caring role, she would talk to local friends (an old friend, who now has PD and is disabled following polio, a friend who is a nurse and a friend from PUK) about the health of her husband. However, she was keen to stress that she didn't want to focus on C when she was with friends. The nurse and neighbour (K) could be called on if she needed help as well as her daughter. She has made friends with other wives who are carers at the PUK group. They meet for a coffee and a chat while their husbands attend activities with PUK.

Gary: Gary is 80 years who lives with his wife, P. She has had Parkinson's for 6 years. He cares for her during 'her waking hours'. On both the negative and positive impact of caring in the COPE scores would indicate that caring is having a detrimental effect. The quality of support appears satisfactory. P attended a day centre for two days per week. He was also receiving some respite from church and Crossroads so that he can undertake activities on his own. The couple have a son and daughter. He had a disabled daughter who died, and he and his wife had cared for her throughout her life. He found caring for his wife different to their daughter since daughter's was a physical disability and she could communicate whereas P is beginning to lose her cognitive function which makes the caring demands different. His surviving daughter is not 'strong' and therefore he doesn't normally ask her to help. The son is supportive and occasionally they do look after the son's children. He is actively involved in the church and recently had extended his contact with TSOs which he found beneficial. Gary had been depressed over the last 18 months and was finding that the demands of the role were increasing. He has a back problem and has been advised at the hospital to take up Pilates which he is doing with the aid of people from the church who stay with P.