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Recruiting young people to sensitive research through negotiations with multiple gatekeepers: turning the 'wheels within wheels'

This article contributes to a growing literature that takes a more nuanced approach to exploring the complexities of relationships and negotiations with gatekeepers. Using our study of young people living with a parent at the end of life as a 'critical case' of sensitive qualitative research, we discuss how far from being a smooth, linear process, participant recruitment was experienced as a series of overlapping challenges, characterised here as 'wheels within wheels'. Each component of this multi-faceted process relied on identifying and engaging with key practitioners who acted as gatekeepers. We discuss how researcher and gatekeeper positionality influenced the outcome of negotiations with gatekeepers, and highlight potential implications for young people in exigent sets of circumstances. If the routes 'in' to access young people are difficult, then this also raises questions about routes 'out' for young people and their access to support when living through challenging times.

Keywords: gatekeepers; young people; participant recruitment; research ethics; end of life

Introduction

In this article we explore the challenges encountered when recruiting young people to participate in a qualitative study of young people's experience of living with a parent at the end of life. This is a more common scenario than one might suppose; while the majority of deaths in the UK now occur in old age, estimated prevalence rates for young people experiencing a parental death are around 5% (Parsons, 2011). The article contributes to a growing literature on the 'messiness' of research practice, (Billo & Hiemstra, 2013; Gillies & Robinson, 2012; McGarry, 2015), with a particular focus on the stage of negotiating access to participants. This may be particularly salient in the context of carrying out qualitative research in social settings and on sensitive topics (Miller, Birch, Mauthner & Jessop, 2012; Punch, 2012).

Opinions on what counts as 'sensitive' research vary (Dickson-Swift, James & Liamputtong, 2008). Nevertheless, as we shall discuss, the combined context of our research topic (living with a parent at the end of life) and the perceived vulnerability of participants (young people) is an example of an area deemed particularly sensitive. Dying and death are difficult subjects to discuss; research commissioned by Dying Matters in 2014[1], reported that the vast majority of the public (83%) believe that people in Britain are uncomfortable talking about dying and death. The construction of an identified sample group as potentially vulnerable within the research process raises issues for site selection and participant recruitment (Heath, Charles, Crow & Wiles, 2007). Access tends to be mediated by key actors who are willing to support the research but who also act as 'gatekeepers'; sometimes more than one set of gatekeepers may need to be approached (Agbebiyi, 2013). The ability to build and maintain collaborative relationships with gatekeepers who facilitate recruitment requires a host of 'people' skills. Such skills need to be particularly fine-tuned when undertaking research involving sensitive topics.

Using our research as a 'critical case' of sensitive qualitative research, we discuss how, far from being a smooth, linear process moving through discrete stages, participant recruitment was experienced as a set of overlapping challenges; characterised here as ‘wheels within wheels’. Each component of this multi-faceted process relies on identifying and engaging with key actors who act as gatekeepers. Our aim is to contribute to a growing methodological literature that takes a more nuanced approach to the notion of gatekeeping by exploring the complexities of relationships and negotiations with key actors. We discuss how researcher and gatekeeper positionality can influence the outcome of negotiations during study recruitment, and we highlight the ethical considerations that inform decision making in the field. Finally we consider the implications raised by our difficulties with recruitment for the young people who were the focus of our research. If the routes 'in' to access young people are difficult, then this also raises questions about routes 'out' for young people and their access to support.

Previous literature on gatekeepers

Recent articles have drawn attention to the role of practitioners as integral to the research process and sought to trouble the notion of ‘gatekeeping’, which has often been

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[1] http://www.dyingmatters.org/news/millions-leaving-it-too-late-discuss-dying-wishes

presented as a discrete and finite action as opposed to a complex and dynamic relationship (Clark, 2011; Miller & Bell, 2012; Crowhurst, 2013). Crowhurst (2013) argues against a mechanistic interpretation of practitioners as gatekeepers, in which the point is simply to get past them and their on-going influence on research is neither acknowledged nor explored. She alludes to a more nuanced body of research in which continuing negotiations with gatekeepers shape and influence researchers' understandings of the process and outcomes of research (e.g. Lewis, 2009; Sanghera & Thapar-Björkert, 2008). In this, fluctuations in the balance of power inherent in researcher-gatekeeper-participant relationships are reflexively interrogated and attempts are made to operationalise the ways in which respect and trust are built up and maintained in and beyond the field (e.g. kennedy-macfoy, 2013; Warin, 2011).

Research has scrutinised the notion of rapport as being vigilant towards the shifting roles and professional responsibilities of gatekeepers and researchers (Reeves, 2010). Researcher positionality in relation to fluctuating definitions of insider/outsider status and the process of working the gap between these dynamic and divergent positions has been explored (McAreavey & Das, 2013). Nevertheless, the positioning of practitioners as adversaries, or 'the enemy at the gate' is sometimes evident (Kendall et al., 2007), and may be more prevalent in sensitive research carried out in the context of health and social care services where access to participants is mediated by tiers of ethical governance, as well as by service mangers and practitioners (e.g. Walker & Read, 2011, Ward & Campbell, 2013). Scourfield (2012) focusses on systemic factors that hinder the process of negotiating access with gatekeepers in this context, and presents gatekeeper responses in terms of their organisational function in repelling the threat of disruption.

One response to the emerging debate on troubling relationships with gatekeepers is to look beyond the terminology of gatekeeping and seek an alternative language to describe the relationships between participants, practitioners and researchers. For example, Notko et al. (2013) present a more nuanced account of their experience of recruiting participants via practitioners who are already working with families. They suggest that practitioners fulfil a valuable role in acting as 'safety nets', enabling the researcher to collect data on sensitive subjects in the knowledge that support is available to participants once the researcher has left the field. Recognising that practitioners occupy multiple positionalities enables a shift in the dynamics of researcher-gatekeeper-participant relationships and suggests alternative frameworks for facilitating negotiation and collaboration. This approach was relevant to our study not only by conditions stipulated in the process of gaining ethical approval but also given our own commitment to ethical practice in terms of ensuring that young people would be able to access support following participation in the study if needed. Our position in relation to working with practitioners had further implications for the sites we chose and subsequent research findings, as we shall discuss following an outline of our project.

The Research Study

The discussions that follow are based on experiences from a doctoral study which set out to explore young people's experience of everyday family life when a parent is at the end of life. This is commonly defined as being likely to die in the next twelve months)[2]. The study involved individual, semi-structured interviews with young people (N = 10) age 13–21 who have a parent identified as approaching the end of life and significant others nominated by a young person (N = 5). The aims of the study were to explore the everyday processes and practices that constitute family life for young people, their experiences of caring and being cared for, and how young people think about their own lives both now and in the future. Prior approval for the study was granted by an NHS Research Ethics Committee (REC).

Young people were recruited to the study via practitioners working at one of eight study sites. The rationale and process of site selection is addressed later in this article. Table 1 shows the number of young people recruited by study site.

[Insert Table 1 about here]

Table 1. Number of young people recruited to the study by study site

Other researchers have highlighted the ethical challenges inherent in conducting research on sensitive subjects, including end of life care (Dickson-Swift, James, Kippen

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[2] The National Council for Palliative Care (NPCC) defines people approaching the end of life as 'likely to die within the next 12 months': NPCC (2012) What about end of life care? Toolkit – Introductory booklet. http://www.ncpc.org.uk/freedownloads?keys=toolkit

& Liamputtong, 2007; Kendall et al., 2007). Ethical considerations pertinent to the study were identified and addressed prior to commencing recruitment. This stage of the research process was necessary for gaining ethical approval for the study, but also involved opening up discussions with practitioners who were in a position to support participant identification, during which we endeavoured to acknowledge and respond to any concerns.

Research ethics

Cultural sensibilities around dying and death in Western societies tend to sharpen the scrutiny of research ethics committees charged with upholding the principle to ‘do no harm’. In the context of qualitative research based on in-depth interviews, researchers have noted a tendency for the notion of ‘harm’ to be conflated with ‘distress’ (Allmark et al., 2009; Gabb, 2010). As Pollock (2012) points out, the biomedical paradigm that informs ethical decision-making by these bodies is largely at odds with the relational, negotiated ethics that guides the conduct of qualitative research. Empirical studies have found participants do not necessarily report the experience of becoming distressed as harmful, and may instead regard it as cathartic or beneficial in their attempts to make sense of their experience (Allmark et al., 2009; Jansen, 2015). While we did not wish to arouse distress for young people and others taking part in our study; we agreed with the stance that distress is not always experienced as harmful. This stance was largely supported by practitioners we consulted during the early stages of study design, many of whom expressed the view that spaces for young people to voice a wide range of emotions that accompanied their experiences of living with a parent at the end of life were limited. The opportunity for young people to take part in a research study that may help to shed light on their concerns was therefore broadly welcomed, even if keeping open such spaces included distress. These suppositions found further support in the process of data collection and we return to this key issue concerning spaces for young people to be heard later in this article.

Research ethics bodies tend to favour a cautious approach in approving language for use in end of life care research (Gardiner et al., 2010). The emotional weight of terms such as ‘end of life’ must be acknowledged. Research also suggests that it is not uncommon for individuals receiving end of life care and their family members to move in and out of awareness, or to have fluctuating degrees of awareness, of prognosis

(Copp & Field, 2002; Richards, Ingleton, Gardiner & Gott, 2013). With this in mind, our study materials for participant recruitment were developed and revised in consultation with young people and practitioners from a young carers' service to ensure that the research topic was introduced appropriately and sensitively. We recognised that practitioners acting as gatekeepers may be particularly sensitive to the potential for distress that the use of end of life terminology may engender or feel uncomfortable opening up conversations on the subject of dying and death (Seymour et al., 2005). As researchers in end of life care, navigating issues between the sensitivity of the language employed and the aim to address the taboos around dying and death and to open up conversations on the topic often involves some compromise. In our research study, we used the language of 'L*iving with a parent who has a serious illness'* but including the question *'Do you have a parent with a serious illness who is not going to get better?'* in the study materials used in participant recruitment.

The decision to approach young people in the first instance via a practitioner who was already in contact with them and/or their family was introduced as a further measure to mitigate the potential for distress. In line with Notko et al. (2013), we viewed practitioners as professionals who could act as 'safety nets', and whilst we believed that this strategy would better enable a sensitive introduction to the research context, it carried implications for site selection and participant recruitment, as we go on to discuss. First, we draw on our experience to provide an overview of the complexity of study recruitment when the research area is deemed to be sensitive and participants are identified as potentially vulnerable.

'Wheels within wheels'; the process of recruitment

The particular obstacles to investigating the experience of young people with a parent at the end of life have not been systematically addressed in the literature although they have been acknowledged by other researchers who have attempted to examine this difficult circumstance (Fearnley, 2010; Kennedy, 2008). Fearnley (2010) describes altering her plan to carry out an observational study of children living with a terminally ill parent due to the difficulty of recruiting children and families; such that the majority of her participants were practitioners who were asked for their opinions on the issues young people face when a parent is dying. We reached a point in recruiting to our study where the challenges of recruiting young people were such that we also considered alternative sources of data to address the topic under investigation. The process of gaining access to young people involved simultaneous negotiations and building of relationships on many fronts. Although ultimately successful, at times it felt we were grinding a complex machine into action; therefore we have applied the metaphor of ‘wheels within wheels’ to illustrate this (Figure 1).

[Insert Figure 1 about here]

Figure 1. 'Wheels within wheels': the active components of participant recruitment

Each ‘wheel’ in this mechanism represents a series of dynamic, interpersonal relationships with social actors whose involvement was crucial to the success of our planned study and carried implications for knowledge production. We discuss each component in turn to explore the processes of building relationships with key actors and consider the impact of power, trust and positionality on the recruitment process. Finally, we consider how methodological issues in relation to study recruitment both reflect and reinforce the positioning of young people in the research process and may have broader implications for hearing the voices of young people living in difficult circumstances.

Local collaborators; site selection and gatekeeping

While site selection for a research study is often the result of a great deal of thought, the actual *process* of accessing sites is given less attention, in particular the ways in which this may be influenced by researchers' contacts and existing relationships with potential gatekeepers. In this section, this is our key focus in addition to considerations of the implications this holds for subsequent knowledge production.

For our study, two local voluntary sector young carers’ projects were identified as study sites as they were already working with eligible young people and providing an ongoing source of support for potential participants. We had considered recruiting young people through schools, but early consultations with local head teachers indicated that school staff may not be aware of when young people are living with a parent at the end of life until after the parent’s death. Furthermore, head teachers were not confident that pastoral support staff in schools would be equipped to provide adequate support to any young people who were identified via this route, therefore we chose not to pursue this option. The young carers' projects had reported encountering increasing numbers of young people living with a parent at the end of life and were preparing resources to meet this need. At a pragmatic level, there were also positive links with the research institution, built around previous academic work and there was the added 'bonus' that the first author had previous connections with the projects having worked for an authority that provided funding to the carers’ projects. In this sense we had willing 'allies' both in terms of access to sites and to potential participants (Bryman, 2008). In contrast, later recruitment routes involved sites with whom we had to develop entirely new research relationships. These different routes highlight issues with regard to the positionality of gatekeepers and the researcher; in terms of the ways in which one is positioned by others depending on perceptions such as one's professional and social identity. As Sanghera and Thapar-Bjorkert (2008) have argued, this may prove ambiguous and contradictory when drawing on different axes of the researcher’s identity.

The first author's previous employment meant that she was already known to key actors in these organisations as a representative of a body with some power and influence over the projects. She had also built up a relationship of trust with key actors through collaborative work with young people and families undertaken during this time. Possibly, given previous connections, these local collaborators may have found it more difficult to decline to support study recruitment than if they had been approached by an unknown doctoral researcher. At the same time, we were reliant on individuals working for the young carers’ projects and implicitly trusted that they would 'deliver'; i.e. identify participants for our study. This is illustrative of how the relational configurations of trust and power are not straightforward or one dimensional; rather as Edwards (2013) argues, they are multiple and fluid. Further, we suggest that the positionality of researchers and local collaborators may influence the process of recruitment in unanticipated ways. In our experience, positive relationships built around prior academic work and the first author's connections created expectations of recruitment from sites where in reality, there were many difficulties in practitioners identifying potential participants. Ultimately we did not recruit any young people via these two carers' projects.

We had to reconfigure our recruitment strategy, but were concerned to do so via sites where we felt the young people and their families would be supported. We thus turned to practitioners in palliative care across several sites; both the practitioners and the sites were previously unknown to the first author. Here, it became apparent that the most effective strategy was to develop supportive collaborations with consultants who in turn 'instructed' or gave permission for nurse practitioners in their teams to approach eligible families for the study. It appeared that these individuals had the authority within their organisational hierarchies to get the 'wheels' moving, utilising power invested in them by virtue of their profession and position in the NHS hierarchy. In return for their input they sometimes made requests of the researcher; for example, to meet additional ethics requirements even though ethics had been approved. For the first author there were contrasts between her prior status via a senior role in a local authority and her experiences in getting consultants on board, to whom she was a doctoral student. The latter set of relationships felt less reciprocal and closer to a research bargain dependent on proving her value. We acknowledge that there is a danger here of presenting the consultants as 'static figures in the field' (Crowhurst, 2013, p. 464) standing at the metaphorical gate which it is in their power to open or not. What is key, as Crowhurst goes on to identify, is to recognise that we are all embedded in, participating in and influencing relations of power. Gaining access through gatekeepers continued to be a dynamic process shaped by multiple and ongoing encounters between the first author and a range of differently positioned actors. Being able to navigate the power dynamics inherent in these research relationships influenced how relationships were operationalised, with subsequent consequences for the unfolding of the research. We further illustrate this by turning to another ‘wheel’ in the recruitment process to consider our relationships and negotiations with practitioners in the field.

Practitioners: gatekeeping in the field

Once site access had been established, there were still many challenges to address in operationalising access to participants. Gaining consultant approvals led to further layers of gatekeeping in terms of liaison with practitioners who made decisions regarding who to approach about the study (or not). It was thus important to invest in building relationships with practitioners in direct contact with potential participants. This entailed an on-going process of establishing trust in the researcher through a series of face to face conversations, attendance at team meetings and presentations of the study protocol. Engaging with gatekeepers in the field proved, as others have identified, an evolving process which in turn had implications for which participants we were able to reach and the knowledge gathered (Crowhurst, 2013). We had little control over the way in which practitioners chose to present the study to potential participants. In particular, the eligibility criteria relating to the prognosis of the young people's parents is acknowledged as difficult, in that it is often not possible to determine with accuracy how long a person has left to live. We found that practitioners tended to adopt a cautious approach to identifying a parent as being at the end of life and chose to exclude young people if there was any sense of uncertainty.

Practitioners appeared to weigh their responsibilities to provide care to family members and to protect family members from additional distress against their agreement to support participant recruitment. It was common for practitioners to report that they had not approached a family about the study because they were not certain if the young person knew their parent was presumed to be in the last year of life. Practitioners work with people at the end of life with the awareness that some people alternate between strategies of acceptance and denial as a means of managing their distress (Copp & Field, 2002; Richards, Gardiner, Ingleton & Gott, 2014). Excluding a young person from the study in this context could be regarded as ethical decision-making on the part of practitioners in enabling young people to protect themselves from openly acknowledging the severity of their parent’s illness. However, it may also have served to extricate practitioners from the necessity of initiating a potentially difficult conversation to determine the extent of a young person’s knowledge.

One entry in the research field notes describes a practitioner putting aside a participant information sheet with the remark, ‘I’m not handing that out’. During the discussion that followed, she explained that do so would involve entering into such a conversation with a young person at what she thought was an inappropriately sensitive time. Another practitioner deliberated for several weeks before finally opting to introduce the study to a family. They immediately agreed to take part in the research.

On a practical level, most NHS practitioners met with their patients during the day when young people were at school or college, and therefore they had little opportunity to approach young people themselves. However, practitioners often stated they did not want to burden families with this request when they had so many other issues to deal with, or when the parent was thought to be in the last few weeks of life. One practitioner explained:

> *…a lot of young people, they don't know it's in the last year and it's only when it comes to maybe the last couple of months, and I think it just ramps everything up a bit more, emotions are higher, problems are more difficult to deal with.*

This echoes Notko et al.'s (2013, p. 401) finding that practitioners applied, 'ethically based criteria such as the family situation being currently relatively stable' when identifying families to approach. However, in doing so practitioners appeared to exercise decisions to operationalise eligibility criteria other than those agreed by the REC. Excluding young people with whom the practitioner had not had a prior conversation concerning their parent's prognosis meant that some young people who were eligible were not approached about the study, and were therefore not provided with an opportunity to decide for themselves whether or not to take part.

The reluctance to engage young people in a discussion about a research study taking place in the context of end of life care contributes to the 'conspiracy of silence' other researchers have noted in some practitioners' dealings with families when someone is dying (Fearnley, 2010, p. 455). One effect may be to disenfranchise young people from participation in research, even though the framework for the ethical conduct of research gives precedence to the individual's right to choose. It may be tautological to point out that young people can neither agree nor disagree to take part in a research study unless they are invited to do so. The dearth of research on young people's experiences of living with a parent at the end of life suggests that practitioners' unease in initiating potentially difficult conversations with young people may be one of the factors that preclude them from this opportunity.

Understanding practitioners' positionality

It is significant to reflect that the actions and decisions of practitioners during the recruitment process were not independent of the organisational environments in which they work, and often reflected the way in which services are managed and delivered. For example, one of the external factors that influenced practitioners relates to the categorisation of 'children' and 'adult' services. Current statutory guidance sets clear and explicit expectations that adult and children's services should work cooperatively together to safeguard and promote the welfare of children[3] and holistic approaches to palliative and end of life care encourage consideration of a person's whole family[4]. Historically however, joint working between adult and children's services in this area has not been strong and these distinctions sometimes appeared to result in young people with a parent at the end of life disappearing into the gap between the remits of these two types of service.

Some palliative care practitioners identified themselves as adult service providers and expressed their lack of familiarity with talking to young people, and their concern about causing distress without necessarily having the means to offer support. Sometimes, a referral would be made to children's services, regarded as better situated to manage any difficult conversations with a young person around their parent's illness. One hospice reported that the inpatient unit did not have specific records of children in a family, and even if they did, may not have their ages recorded. In addition, sometimes the pressure of workloads led palliative care practitioners to limit their attention to the parent in need of their services and not to seek out other family members who may be in need of support.

In contrast, practitioners from young carers' services mostly work with young people and may have limited contact with parents. Whilst they are experienced at supporting young people with very complex needs, some practitioners stated that they lacked the necessary skills to address the difficult subjects of dying and death, and would also seek to refer on to a more specialist service such as a young person's bereavement service. The demands of managing increasingly high workloads were also apparent for this group of practitioners, who sometimes reported that they had little access to the additional training and support they felt they needed for such emotionally sensitive work. Thus, our view of practitioners being the potential providers of a 'safety net' to support young people if required was not as straightforward as envisaged.

The framing of sensitive subjects such as dying and death as taboo, and of young people as categorically distinct from adults, implies that a particularly specialist subset of skills is required to address such issues with young people, beyond the skills normally held by adult health and social care practitioners or young people's support

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[3] Children Act 2004 sections 10 and 11: http://webarchive.nationalarchives.gov.uk/20100113205508/opsi.gov.uk/acts/acts2004/ukpga_20040031_en_1

[4] Gold Standards Framework in End of Life Care: http://www.goldstandardsframework.org.uk/

workers. This can both undermine the expertise of practitioners, and can lead to the marginalisation of many young people as participants in research. It may also act to exclude young people from being offered the help they may need.

The social construction of youth engenders distinctions being made between ‘adults’ and those who are ‘not yet adults’ and who are therefore deemed to require advice and guidance from adults (Wyn & White, 1997). This construction assigns young people to a position of relative powerlessness and may also ‘silence and exclude them’ (Alderson, 2004, p. 105). As Heath, Charles, Crow and Wiles (2004, p. 16) suggest 'the assent or refusal of the gatekeeper is often given as a proxy for the assent or refusal of potential research participants, without actually consulting with them first'. In our study, a further ‘wheel’ in gaining access to young people was their parents.

Parents as gatekeepers

Although the majority of participants in the study were over the age of 16, most were recruited via a parent, since many of the study sites were providing a palliative care service to a parent in the family who was approached about the study in the first instance. A number of practitioners reported occasions when a parent had declined the opportunity for their son or daughter to participate in the study. Whilst there was no obligation for parents to give a reason for their refusal, it was sometimes stated that the parent wished to protect their child from any distress their involvement may incur. Some negative responses were attributed to the physical or emotional health of the parent. Parents in receipt of palliative care were described by practitioners as too ill to properly consider the request, or alternatively, in some cases described as angry and disengaged with services in general.

Parents who agreed to their son or daughter taking part were often motivated by wanting something for their children, and not just themselves. They described their young people as needing, but lacking direct support, and some parents wanted to highlight the lack of appropriate services for young people in their son or daughter’s situation.

The deliberations of parents approached during this study were illuminated by research exploring the relationship between illness and motherhood as key sources of identity for women (Elmberger, Bolund & Lützén, 2005; Wilson, 2007). The authors of these studies describe how women struggle to be ‘good’ mothers in spite of their poor health, and therefore strive to reinforce this moral identity in whatever ways they can. Similarly, for the mothers and fathers in this study, the decision over whether to give consent to a young person's participation in research may best be interpreted in the light of Notko et al.'s (2013, p. 401) comment, 'It is possible that decisions of this kind…are among the last ones they have the power to make - and therefore they are closely guarded'. Parents at the end of life may be more inclined to protect young people from the potential distress their involvement in a study may incur as it affords them an opportunity to 'parent' their child when other forms of parenting may no longer be available to them.

Young people

Once we had all the 'wheels' turning and had gained access to young people, there was no guarantee the young person would agree to take part in the study. We often do not find out why people do not wish to participate in research studies and this was also true of young people in our study who did not want to take part. Nevertheless, it is reasonable to suppose that some young people may wish to protect themselves from an encounter they may find distressing; particularly if there is a risk that it might force them to confront something they would rather not 'know'. One participant presented this ambivalence about knowing the details of his mother's illness as follows:

> *I knew enough for me … I don't necessarily ask but, you know, she always just lets me know … I don't really push for any information. I feel that I could ask but, I just don't really.*

It may be considered unethical to undermine a young person's efforts to preserve a sense of ambivalence in the context of their parent's prognosis, or to intrude into areas they would rather remain private (Phelan & Kinsella, 2013). A young person's refusal to engage with the study could therefore be interpreted as a positive indication that sufficient measures had been put in place to enable this decision to be taken, and this particular strategy to be maintained.

However, research on young people's responses to the death of a parent demonstrate that young people can and do talk to researchers about 'the trouble loss brings' (Jamieson & Highet, 2013, p. 135). Some researchers have found participation in focus groups is particularly effective with young people (Coombs, 2014) but our experience was that individual interviews also worked well. Once recruited, young people proved capable of providing thoughtful and articulate accounts of living with a parent who is at the end of life. However, those whom we were able to access often had few opportunities or spaces where they felt able to be open and talk about their everyday family lives. Some young people stated that they wanted to be heard and for people - including adults and their peer group - to understand something of the many facets their experience encompassed. One participant expressed this as follows:

> *I think they should just understand people better instead of judging. I think they should walk in our shoes for once and see how we deal with it.*

It is this assertion that underlines the importance of grinding into motion the ‘wheels within wheels’ that sometimes act against the recruitment of young people to research studies, especially when the subject matter is sensitive.

Conclusion

In this article, we have identified and scrutinised the individual components that together constitute the complex process of recruiting young people to a study exploring the experience of living with a parent at the end of life. We have described ways in which each of these components can become stuck during the course of this operation, invariably stalling the mechanism and resulting in a research process that is far removed from the ideal of the well-oiled machine presented in text book accounts. By isolating the ‘wheels within wheels’ and examining each in turn, we have been able to elaborate on why it proved so difficult to recruit young people to this study. Gaining access to young people for a sensitive study is contingent upon developing and maintaining a set of nested relationships with key actors. It entails a multi-faceted operationalisation of the multiple relationships involved; encounters which have a profound influence on the shaping and unfolding of the whole of the research process.

Recruitment can thus be conceptualised as a process, contingent on the decisions of a number of actors, including the researcher, and on the dynamic relationships between these actors over time. It is important to be aware that individual decisions about research participation are relational and influenced by moral deliberations to ‘do right’ by others. In reaching decisions to negotiate access or to take part, practitioners, parents and young people considered the potential impact of their involvement on others (indeed, for young people under 16, they are obliged to negotiate their participation with their parent).

Practitioners are often a valuable resource for the researcher in terms of gaining access to participants in health related research. It is essential to build relationships with key practitioners as these dynamic interpersonal relationships are the 'wheels' of the process. This includes working to procure practitioners' commitment to invest precious time to the research project in question. Understandably, their priorities often differ from those of the researcher; sometimes in ways which can be frustrating (although understandable) to the researcher. In our study, the practitioners who were our key source of access to participants prioritised the welfare of their patients (the young people's parents). Their assessments of their patients' prognosis and sensitivities around not adding further burdens to families dealing with an approaching death meant they had additional ethical considerations to those contained within our ethics approval. Furthermore, some were reluctant to open up difficult conversations, especially with the patient's children and quite often practitioners situated within adult services had little direct contact with young people themselves. Such factors are frequently beyond a researcher's control yet have significant implications for knowledge production.

In our research field, some researchers have applied the metaphor of 'the elephant in the room' to describe the tendency for practitioners to avoid discussions of dying and death with individuals and family members, and in particular young people (Fearnley, 2010: Kirkby, Broom, Good, Wootton & Adams, 2014). At the risk of over-extending this metaphor, it is time the elephant was taken out and released into the wild. Death is a common presence in the everyday lives of young people (Highet & Jamieson, 2007) and the absence of opportunities for young people to talk about their feelings when someone close to them is dying is a factor indicated in the poorer outcomes experienced by some young people facing bereavement (Kennedy & Lloyd-Williams, 2009). When talking to practitioners, we were mindful of the need to acknowledge their concerns about the potential to cause distress to young people, and to provide positive illustrations of the benefits of taking part to counterbalance the perceived risks. For example, while there is little evidence about the support needs of young people prior to the death of a parent, evidence suggests earlier support may improve long term outcomes for young people (Christ and Christ, 2006). At a community level, much more needs to be done to normalise talk about dying and death, particularly in schools and in the real and virtual places young people visit to access support.

Gathering young people’s accounts of their experience of living with a parent at the end of life is undoubtedly sensitive work; but without it, the prospect of identifying and alleviating distress in young people must be poorer. There are implications here not just for research but also for young people in sensitive or challenging sets of circumstances. If the routes 'in' to access young people are difficult then this also raises questions about routes 'out' for young people in terms of whose voices are heard and importantly, about young people's access to support when living through challenging times.

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