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Doctoral Thesis:

The Experiences of Staff Supporting People with Intellectual Disabilities with Dementia, Death, and Bereavement

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Word Counts

	Abstract	Main Text	Appendices (including tables, figures and references)	Total
Thesis Abstract	299	-	-	299
Literature Review	160	7,820	5,877	13,857
Research Paper	183	7,250	5,672	13,105
Critical Appraisal	-	3,997	612	4,609
Ethics Section	-	4,300	6,386	10,686
Total	642	23,367	18,547	42,556

Abstract

This thesis is divided into three sections. The first section comprises a literature review, which aimed to understand the experiences of staff in supporting clients with intellectual disabilities with issues of death, dying, and bereavement. A metasynthesis was conducted to review 13 papers meeting the inclusion criteria. Three themes were developed: (1) Talking about death is hard: Negotiating the uncertainty in death, dying, and bereavement; (2) The commitment to promoting a “good death”; and (3) The grief behind the professional mask. An overarching theme, “A cautious silence: The taboo of death,” was also developed. The taboo culture surrounding death in intellectual disability services is discussed in relation to relevant literature, and clinical recommendations are offered.

The second section, a research paper, explores the experiences of ten paid staff who have supported a person with an intellectual disability and dementia within a supported living setting. An interpretative phenomenological analysis was used. Four themes were developed: (1) The value of the pre-existing relationship to paid staff as dementia progresses; (2) Finding ways to connect when reciprocity has gone; (3) Resisting dementia “creeping in” and taking control; and (4) The stronger the pre-existing relationship, the greater the emotional cost of dementia. The findings support previous research, suggesting that intellectual disability services are well-placed to support people with intellectual disabilities with dementia, due to staff’s in-depth knowledge and well-established relationships. However, the findings also highlighted the emotional cost of this role to staff. Recommendations for clinical practice and ideas for further research have been offered.

In the final section, the critical appraisal, I offer my reflections on the process of conducting the aforementioned research with paid staff supporting people with intellectual disabilities and dementia. I explore the process of developing the research idea, and reflect on the emotional nature of the topic.

Declaration

This thesis records work undertaken for the Doctorate in Clinical Psychology at the Division of Health Research at Lancaster University from June 2014 to May 2015. The work presented here is the author’s own, except where due reference is made. The work has not been submitted for the award of a higher degree elsewhere.

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Date:

Acknowledgements

I would like to begin by thanking Matthew, Maggie, Margaret, Paul, Katee, Linda, Andrea, Rose, Sophie and Sarah[1], my research participants, who kindly gave up their time to meet with me. It was a privilege to have the opportunity to listen to your stories and I hope that I have done them justice. My thanks also go out to those who supported my recruitment.

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Finally, thanks are extended to my friends and my training cohort. You have provided the much-needed laughs along the way and have always had faith in my abilities. Even those of you that have asked when “the big essay” is due in!

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[1] All pseudonyms

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Section One: Literature Review

Supporting People with Intellectual Disabilities with Issues of Death, Dying, and Bereavement: A Metasynthesis

Word Count: 7980

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[1] See Appendix 1-A for author guidelines

Abstract

People with intellectual disabilities have historically been excluded from knowing about death, dying, and bereavement. Evidence suggests that staff in intellectual disability services play a valuable role in improving understanding of these issues in those they support. This metasynthesis aimed to understand the experiences of staff supporting people with intellectual disabilities with issues of death, dying, and bereavement. Thirteen papers were identified following a systematic review of six databases. Three themes were developed following a line of argument synthesis: (1) Talking about death is hard: Negotiating the uncertainty in death, dying, and bereavement; (2) The commitment to promoting a "good death"; and (3) The grief behind the professional mask. An overarching theme, "A cautious silence: The taboo of death," was also developed. Findings highlight the need for a more open culture around issues of death, dying, and bereavement in intellectual disability settings, which could be promoted through staff training and support.

Keywords: Intellectual disability; death; dying; bereavement; grief; staff.

1. Introduction

In 2013, there were approximately 900,900 adults with intellectual disabilities (ID) in England, a fifth of whom were known to specialist ID social care services (Public Health England, 2014). Around a third of adults with ID known to local authorities in 2012-2013 lived at home with family or friends, whereas a quarter lived in some form of community residential setting (Public Health England, 2014),with varying degrees of staff support depending on their individual needs (Gone, Hatton & Caine, 2012; Public Health England, 2014). The “Transforming care for people with learning disabilities – next steps” guidance from NHS England (2015) outlined plans to support people with ID (PWID) to live independently within the community and avoid unnecessary hospital admissions. Many of those living in community residences receive input from community ID teams, comprising a range of health and social care professionals, such as clinical psychologists, occupational therapists and psychiatrists (Gone et al., 2012).

1.1. Ageing and mortality in PWID

As the population of older adults with ID increases (Public Health England, 2014), a rise in the number of over 50’s using ID services in the next 15 years is anticipated (Emerson & Hatton, 2011). PWID are known to die up to 20 years earlier than the non-ID population (Public Health England, 2014). Particular conditions related to ID are associated with life-shortening degenerative illnesses, such as Down syndrome, which is linked with the early onset of Alzheimer’s disease (Zigman et al., 2004). The median age of death in PWID in England in 2012 was estimated to be 58 (Public Health England, 2014), compared to the general population estimate of 82 for a man and 85 for a woman (statistics for England and Wales in 2010; Office for National Statistics, 2012). Todd (2005) suggests that many PWID will end their lives in community residential settings and the increased life expectancy of

PWID means that more of this group are experiencing bereavements than ever before (Dodd & Guerin, 2009).

1.2. Concept of death in PWID

The historical belief that PWID were not capable of experiencing grief (e.g. Hollins & Kloeppel, 1989) has since been disputed (see Brickell & Munir, 2008; Dodd & Guerin, 2009). It has been increasingly acknowledged that PWIDs' experiences reflect the negative effects of bereavement described by the general population (Dodd & Guerin, 2009; Harper & Wadsworth, 1993; Hollins & Esterhuyzen, 1997; McEvoy, MacHale & Tierney, 2012). One explanation for this false assumption is that paid staff often misattribute expressions of grief as behaviours that challenge, or symptoms of psychiatric disorders (MacHale & Carey, 2002).

Harper and Wadsworth (1993) suggest, however, that expression of grief by PWID is not dependent on a full comprehension of the concept of death. A full concept of death is often conceptualised using Piaget's (1960) framework, whereby an individual understands the causality, irreversibility/finality, non-functionality/cessation, universality and inevitability of death. Death concept varies widely in PWID and is thought to be better understood by those with higher cognitive and adaptive functioning (McEvoy et al., 2012). McEvoy et al. (2012) found that a full understanding of death was evident in less than a quarter of 34 participants interviewed following the use of vignettes depicting death-related issues. Only two participants were limited in their comprehension of death, with the majority (70%) having partial understanding. This study supported earlier findings that the majority of adults with ID possess only partial comprehension of the concept of death (Dusart, 2008; Harper & Wadsworth, 1993; McEvoy, 1989; McEvoy, Reid & Guerin, 2002).

1.3. The exclusion of PWID from issues of death, dying, and bereavement

To date, research exploring experience and understanding of death and bereavement, death-related rituals (e.g. funerals), and bereavement support directly with PWID has been limited (e.g. Forrester-Jones, 2013; Gilrane-McGarry & Taggart, 2007; McEvoy et al., 2012; McRitchie, McKenzie, Quayle, Harlin & Neumann, 2014).

Many PWID are not informed of the deaths of friends or family and may be excluded from associated rituals (McRitchie et al., 2014), despite evidence that concrete experiences of issues related to death and dying can help PWID to understand the abstract concept of death (Dusart, 2008; Harper & Wadsworth, 1993). This exclusion is consistent with the concept of disenfranchised grief, which is defined as “the grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported” (Doka, 1989, p.4).

Likewise, PWID have often been excluded from discussions around their own mortality, terminal diagnosis (Tuffrey-Wijne, Bernal, Hubert, Butler & Hollins, 2010), and terminal care (Bernal & Tuffrey-Wijne, 2008; Todd, 2004), with staff reportedly making the decision to do so early in the person’s illness (Todd, 2004). Research by Tuffrey-Wijne and colleagues (Tuffrey-Wijne et al., 2010; Tuffrey-Wijne et al., 2013) highlighted possible reasons for staff not disclosing bad news to PWID. These included the idea of “ignorance is bliss” (p.17, Tuffrey-Wijne et al., 2010), avoidance of potential burden on the individual (Tuffrey-Wijne et al., 2010; Tuffrey-Wijne et al., 2013), and an assumption or an assessment that the PWID will not understand or may not fully appreciate the time-scale of the illness (Tuffrey-Wijne et al., 2013). Staff specific factors also influenced such decisions, including difficulties managing their own emotions, lacking knowledge about prognosis, and differences in opinion about disclosure (Tuffrey-Wijne et al., 2013).

1.4. Involving PWID with issues of death, dying, and bereavement

Although evidence of exclusion from issues of death and dying continues to emerge, there are examples to the contrary. For example, when being given information about an anticipated or recent bereavement, PWID reported feeling proud to have been involved (McRitchie et al., 2014). Opportunities to be involved in bereavement rituals, including viewing the body, attending funerals, visiting the grave, and reminiscence about the deceased have also been reported by PWID (McEvoy et al., 2012; McRitchie et al., 2014).

PWID have expressed a desire to be involved with issues of death and dying (McRitchie et al., 2014), although McEvoy et al. (2012) and Tuffrey-Wijne et al. (2013) emphasise that level of involvement should be responsive to individuals' preferences, as some may prefer not to participate in some aspects of this. It is therefore concerning that only 47% of the 34 PWID included in a study by McEvoy et al. (2012) felt that they had received adequate bereavement support.

1.5. The role of ID services in death, dying, and bereavement

Despite reported inconsistencies in ID services involving PWID with issues of death, dying, and bereavement, staff in these services are well-placed to recognise and support issues of bereavement (Dodd & Guerin, 2009; Gilrane-McGarry & Taggart, 2007; Wiese, Stancliffe, Dew, Balandin & Howarth, 2014) and PWID' own mortality (Wiese et al., 2014).

Clinical psychologists are often called upon to offer psychological consultation, support and therapeutic interventions to PWID and staff for a range of emotional and behavioural issues (Corbett, 2007). However, to consider the most appropriate way for staff from ID services to support PWID, it is necessary to gain a better understanding of their experiences in supporting them to understand issues related to death, dying, and bereavement.

1.6. Systematically reviewing the literature

Given the still limited but growing body of qualitative literature related to the experiences of ID staff in supporting PWID with issues related to death, dying, and bereavement, it is timely to conduct a systematic review of the available qualitative research. A thorough literature search identified several papers described as "reviews" with potential relevance to this topic area (Brickell & Munir, 2008; Dodd, Dowling & Hollins, 2005; Dodd & Guerin, 2009; Dunkley & Sales, 2014; Tuffrey-Wijne, 2003; Tuffrey-Wijne, Hogg & Curfs, 2007). However, on further examination some of these reviews were not considered systematic in their approach (as described by Shaw, 2012). Furthermore, they held a different focus to this review. For example, Dodd et al. (2005) considered how PWID are affected clinically by bereavement, and Dunkley and Sales (2014) focused on the provision of palliative care for PWID. Shaw (2012) argues that systematic reviews are crucial in ensuring practice is based on good quality evidence. To ensure the support offered to PWID with issues of death, dying, and bereavement is of high quality, it is important to establish the current state of knowledge in this specific area. This is the focus of the current review.

1.7. Aims of the qualitative metasynthesis

By conducting a systematic search of the literature using multiple search databases, I aim to examine and synthesise the available qualitative research exploring the experiences of staff from ID services in supporting adults with ID in relation to issues of death, dying, and bereavement. Using a meta-ethnographic approach (Noblit & Hare, 1988), I aim to collate the findings of this research, reviewing, transforming and synthesising them to generate a deeper understanding of the experiences of the participants concerned. Meta-ethnography is a form of interpretative synthesis which aims to go beyond the original interpretations made in each individual study, by developing new higher-order interpretations, which explain the research findings as a whole (Pope, Mays & Popay, 2007). Findings of the metasynthesis will be presented and their clinical implications will be discussed.

2. Methods

2.1. Searching for studies

The search strategy for this metasynthesis was informed by guidelines proposed by Shaw (2012). Before beginning the search, a research question neither too broad nor too narrow was developed (Walsh and Downe, 2005). This metasynthesis aimed to address the research question: "What are the experiences of staff from ID services in supporting adults with ID in relation to issues of death, dying, and bereavement?"

To develop a thorough search strategy, the constituent parts of the research question were determined. The SPIDER tool (Cooke, Smith & Booth, 2012) is one of several tools available which aim to maximise the retrieval of relevant qualitative research by ensuring search terms are sensitive to the research question. This tool encourages the consideration of search terms for each of the following: S – sample; PI – phenomenon of interest; D – design; E – evaluation; and R – research type. An initial search revealed that these domains were too specific. An adaptation of this tool was therefore used to structure the identification of search terms, whereby the evaluation domain was excluded, and the design and research type domains were combined (Table 1).

<INSERT TABLE 1 HERE>

MEDLINE, PyschInfo, Academic Search Complete, CINAHL, EMBASE (with MEDLINE results excluded as a limiter) and Web of Science were systematically searched in January 2015. Free search terms and database-specific subject headings were combined for each domain identified, using the Boolean instructor "OR". Free search terms (Table 2) were identified by generating relevant words and synonyms, including those commonly used within the literature on this topic. Truncations were used where appropriate. Database-specific subject headings relevant to the topic were exploded where appropriate (Table 3).

<INSERT TABLE 2 HERE>

<INSERT TABLE 3 HERE>

This resulted in four separate searches, which were combined using the Boolean instructor “AND”. Results were then limited by English language on all databases (due to no translation facility), and by peer-review (for basic quality assurance) where this function was available (PsychInfo, Academic Search Complete and CINAHL). The initial search yielded 623 papers (MEDLINE=106, PsychInfo=100, Academic Search Complete=124, CINAHL=103 , EMBASE=75, Web of Science=115). Titles and abstracts of each article were reviewed to determine whether qualitative methods were used and their relevance to the research question. Where this was unclear, articles were retained at this stage. 114 papers remained after this initial review (MEDLINE=21, PsychInfo=26, Academic Search Complete=25, CINAHL=19 , EMBASE=0, Web of Science=23). Only 35 of these remained once duplicates were removed. Advice on this search strategy was sought from a specialist librarian.

Papers were included if: (i) they were published in English; (ii) they were published in a peer-reviewed journal; (iii) they used qualitative methods and demonstrated qualitative analysis; (iv) they reported the experiences of staff supporting adults with ID with issues of death, dying, and bereavement.

Papers were excluded if: (i) they used mixed methods where qualitative data could not be extracted; (ii) data analysis was not inductive (e.g. framework analysis), (iii) data from staff from ID settings could not be distinguished from staff from other settings (e.g. palliative care), (iv) it was unclear whether staff members were members of ID services, (v) their data related to palliative care in general, without a focus on death, dying, and bereavement.

Following application of these criteria, 11 papers remained. Reference lists of these articles were reviewed, yielding two further papers. Thirteen papers, reporting on 11 different studies, were included in the metasynthesis (see Figure 1 for a flow chart illustrating this search strategy).

<INSERT FIGURE 1 HERE>

2.2. Characteristics of selected studies

The key characteristics of the included papers are outlined in Table 4. The 13 papers (which I will refer to by study numbers S1 to S13, in order that they can easily be distinguished) were published between 2005 and 2014, and drew on 11 different samples. Participants totalled 416 across the 11 samples; according to the inclusion and exclusion criteria, 294 (study samples ranging from 4 to 57 participants) of these were eligible for inclusion in the metasynthesis. Studies using the same samples (S5 and S6 = one sample, and S11 and S12 = one sample) all met the inclusion criteria and had different research questions. Samples were from England, Wales, Ireland, Australia and USA. Of those that stated participants' ages, this ranged between 19 and 75 years old. Participants' gender was not always specified.

<INSERT TABLE 4 HERE>

Studies employed a range of qualitative methods, including qualitative questionnaire surveys (S1, S3), interviews (S2, S4, S8-S13) and focus groups (S5-S7, S10-S13). S3 used mixed methods, however the qualitative data was extractable from quantitative analysis. Analyses included interpretative phenomenological analysis, phenomenologically informed methods, thematic content analysis and grounded theory techniques. While the approaches used in these studies draw on different methodologies and epistemologies, each study was deemed to offer a valuable contribution of the diverse experiences of staff from ID services.

2.3. Appraising the quality of the selected studies

The selected studies were appraised according to the Critical Appraisal Skills Programme (Critical Appraisal Skills Programme [CASP], 2013), a tool designed to assess the quality of health related research. To add rigour to this process, three papers were also appraised by a peer who is equally experienced in use of the CASP. Any discrepancies between scores were discussed with the reviewer, and a final score was agreed upon.

Each paper was reviewed and rated as being weak (1), moderate (2) or strong (3) in relation to ten questions (Table 5). A total score was calculated for each study (scores could range from 8 to 24). These ranged from 9 to 24 (mean=9.5). Some of the lower scores were related to poor reporting or journal word restrictions, rather than necessarily being of a poor quality. The domain with the lowest scores (CASP question six) was that assessing whether the authors had addressed their relationship with participants.

The intention of appraising quality was not to exclude studies with lower scores using an arbitrary cut-off, but to consider quality when synthesising the studies as a way of ensuring that interpretations were not biased towards the weaker studies. For example, data from two lowest scoring papers (S3 and S4) were used only to enhance themes that had already emerged from higher scoring papers.

<INSERT TABLE 5 HERE>

2.4. Analysing and synthesising the selected studies

Guided by the stages of meta-ethnography outlined by Noblit and Hare (1988), the results and discussion sections of each paper were reviewed and salient information related to the research question was extracted. This included the metaphors, phrases, concepts and quotations used by the authors to describe their interpretation of their original data, which were entered into a data extraction table. Connections within, and across studies were considered and a “line of argument” synthesis (Noblit & Hare, 1988, p.62) was implemented to develop themes. The aim of this was to "discover a 'whole' among a set of parts" (Noblit & Hare, 1988, p63), that is, to develop an overall interpretation of the interpretations applied by the authors of each individual study. The themes identified aimed to be sensitive to inconsistencies and tensions across the studies, while capturing the breadth of findings.

3. Results

Three themes, (1) Talking about death is hard: Negotiating the uncertainty in death, dying, and bereavement; (2) The commitment to promoting a "good death"; and (3) The grief behind the "professional mask", were developed through the synthesis of the 13 papers. An overarching theme, "A cautious silence: The taboo of death" was developed to represent what was learnt from the synthesis process. These will be discussed below, with supportive quotes[2] from the 13 papers. The contribution of papers to each theme is provided in Table 6, and a more detailed example of how the data from two papers contribute to an overall theme is provided in Appendix 1-B.

<INSERT TABLE 6 HERE>

3.1. Talking about death is hard: Negotiating uncertainty in death, dying, and bereavement

This theme encapsulates how participants' uncertainty and anxiety towards talking about and supporting PWID with issues of death, dying, and bereavement influenced how they engaged them about this.

Many participants had not experienced the death of someone they supported, nor had they previously supported someone with a bereavement. Without direct experience, there was considerable uncertainty around talking about death, dying, and bereavement: "...and how to explain it to the [service user] and what are the appropriate phrases to use to explain death and what … to not say." (S7, p.591). This uncertainty was accompanied and reinforced by assumptions about whether PWID should be engaged regarding issues of death, dying, and

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[2] The omission of words within quotes is indicated by three ellipsis points (…).

bereavement, leading participants to avoid such conversations. These included a belief that death understanding was dependent on severity of ID: “I think there are differences across the levels, I think it depends how severe the disability is … In my own area where I work I don’t think any of the clients would have any understanding whatsoever.” (S7, p.589). Another assumption was that bereavement support was limited by PWIDs’ difficulty or inability to express emotions: “They don’t have the capacity to understand, or they do understand but they don’t feel sorry or have any feelings whatsoever.” (S12, p.575). Some participants believed that the PWID they supported were not ready or willing to talk about death, and consequently did not discuss a death in the residence with them:

> Hit and miss – most will just know if their friend is no longer sitting on the bus with them and ask “where is so and so”? …People don’t like to talk about these things – it’s … doom and gloom, very taboo. (S1, p.248)

Most participants, however, believed PWID were entitled to know about death, dying, and bereavement and were capable of experiencing grief: “They should be included in the process … There should never be the attitude ‘Oh, they don’t understand anyway.’” (S3, p.192). Preconceptions were often challenged when staff did attempt such conversations.

Participants cited numerous approaches which facilitated conversations about death, dying, and bereavement with PWID. One such facilitator for many participants was an actual bereavement, which gave participants a means to talk about something abstract in a much more concrete way. For example, involving PWID in funerals was reported to be effective in educating them about death and helped them to gain closure:

> Since [clients actively participate in the rituals] it’s been really, really good … So they do the eulogy … put pictures up of the person and everything … and they get the message now. Afterwards they say “they’re gone now”. (S13, p.685)

Other concrete opportunities to talk about death included viewing the body before the funeral, visiting the cemetery and using memorials to remember the deceased. Some participants, particularly those with previous experience of supporting PWID with issues of death, dying, and bereavement, used opportunities to talk about this on a day-to-day basis. For example, one participant reported using the life cycle of a plant to teach a PWID about the human life cycle.

Considerable uncertainty was expressed about how to support PWID with grieving. Many participants remarked upon the difficulties identifying grief in PWID, particularly when the person had impaired communication. Participants more confidently managed and supported grief when it resembled what they perceived to be culturally “normal” grieving, such as crying. However some recognised the need to look harder for grief in PWID, as it did not always manifest as expected: “At the same time they might be gone off their food or refusing to go to activities. The trouble is staff might think there was another cause to these symptoms.” (S8, p.123).

Many participants described improvising with bereavement support, drawing on personal experiences of grieving as a guide: “Interviewer: ‘Where do the ideas come from?’ Staff: ‘[it’s] what I’d do myself if I lost somebody.’” (S7, p.591). While this appeared helpful, there was a sense of discomfort around use of improvisation: “I don’t know, you hopefully do it right, and you don’t know if your [sic] doing it right.” (S7, p.592).

This “path of discovery” (S7, p.594) was evident for many participants, who felt they were just doing their best in the absence of feedback, training or support. Their uncertainty in supporting PWID with issues of death, dying, and bereavement was evident through their desire for policies and procedures to follow, which for some suggested a fear of the unknown: “We should all know what is available … we need policies in place and everything with great clarity.” (S7, p.592). Participants appeared to be more comfortable discussing death when they had a framework. Frameworks included policies detailing what to do following a person's death, religious and spiritual frameworks, or resources to facilitate difficult conversations: "I play the video again and say, 'Okay guys, remember? Her brain is sick. Mark's brain is sick too. What happened at the end of the movie? Did Mary get better? No. What happened to Mary? Mary died.'" (S13, p.685). Participants recognised that their own lack of knowledge about death, dying, and bereavement had the potential to limit their engagement with PWID. Some participants discussed their desire for training: "I think bereavement awareness is the big key … it's actually having [staff] talk about it … help them [to] feel comfortable talking about bereavement with one of the service users." (S7, p.593).

While there were some inconsistencies between participants in their engagement of PWID in discussions about death, and the bereavement support they offered, the majority made attempts to address this. Conversely, participants were much less likely to initiate discussions with a person about their own death. In those studies addressing this issue (S9-S11, S13), some participants believed PWID were entitled to know they were dying, so that they could plan their remaining time. Nonetheless, this did not reflect the reality for most participants. Many of the assumptions discussed above were perceived as barriers to such conversations. Non-disclosure was often considered to be in the person's best interests, to protect them from distress: "He's suffered all his life so why make it worse now. I think it was the right thing to do … What good would it have done? … It was almost a sudden death for him." (S9, p.223).

Maintaining secrecy was difficult for participants. One participant acknowledged that non-disclosure of a person's imminent death was often a way of protecting the staff member rather than the PWID: "We label that as 'oh, the person is not ready for it or they couldn't cope,' but actually it is us that can't cope with it sometimes" (S10, p.237).

This theme illustrated how participants' uncertainty influenced how they engaged with PWID about death, dying, and bereavement, and suggested that the greater their uncertainty, the more challenging these conversations were.

3.2. The commitment to promoting a "good death"

This theme captures how participants felt privileged to support PWID to have "good deaths" (S5, p.146; S9, p.219). They were committed to doing so despite their own anxieties and perceived lack of support.

Participants expressed anxiety about being involved in the process of a person's dying. This lack of confidence often related to their limited experience and a fear of the unknown: "I thought she can't die now … because I won't know what to do … I've no experience so what do I do?" (S6, p.195). Even for those who had supported someone through their death in their job, this fear was often exacerbated by the perceived lack of support throughout this process. This led some participants to worry about their ability to support a death: "We are employed as support workers, so where's the support? I've never done anything like it before and I was just frightened that I'd do something wrong." (S9, p.221).

Nevertheless, many participants were committed to supporting people with end-of-life care and felt that their strong relationship with the person enabled them to provide a "good death" (S5, p.146; S9, p.219). A good death was conceptualised by PWID dying in familiar surroundings amongst familiar people: "…that would honestly pain me to think that he was somewhere new without his familiar surroundings, without the people that he's worked with for close on ten years." (S12, p.576).

A home death was not always possible, for example, when specialist care or equipment was required in a hospital setting. These so-called "bad deaths" (S6, p.196; S9, p.221) created feelings of anger, guilt, and a sense of failure. For some, the perceived irony of dying in hospital was unfair:

> A hospital death would have been a bad death … I don’t think it is right that people should go back into an institution to die. That would be wrong, wouldn’t it? I would say that this was her home. (S9, p.221)

Hospital care was experienced by participants as inadequate for the PWID’s needs. This related to the lack of in-depth knowledge of the person held by hospital staff, which participants thought was essential to a good death. This reinforced participants’ commitment to enabling home deaths in future: “He died in hospital and … the nurses didn’t have time for him. I’d crawl around on my hands and knees before anybody took another of our residents away from me like that.” (S9, p.221).

It was acknowledged by some participants, however, that staff yet to experience the sometimes brutal reality of a home death held an idealised view of this, and that there was a potential to lose sight of what was best for the person:

> We would have seen it as a failure. But did we do the right thing I’m not sure … There was a tremendous will to do it but I’m not sure it was right for everyone … It’s got to be about quality for that individual. It shouldn’t be about how far are we willing to go. (S9, p.223)

Other participants acknowledged the challenge of supporting a death and the lack of appropriate support to manage this in community residences: “Maybe in a hospital you’d have support round you. Here I felt we were on our own.” (S9, p.221)

This theme recognises the commitment of participants to ensure that PWID die a good death without unnecessary suffering. However, this dedication was often costly to staff, who felt uncertain and unsupported in doing so.

3.3. The grief behind the “professional mask”

This theme encapsulates the emotional impact on staff who supported PWID with issues of death, dying, and bereavement. This resulted from their relationships with the deceased. It describes how participants felt unsupported by management in dealing with their grief due to a lack of recognition of this relationship.

Participants described being “embedded” (S2, p.189) in the lives of those they supported, which often resulted from the longevity of their support relationship. When a person died, they experienced considerable grief. For some participants, there was a perceived danger of staff grieving at the expense of those they supported and an expectation to prioritise their professional duties over their own grief:

> I was really fond of her … and when she died I had to walk out of the room and attend to somebody else. There was nobody to take me aside and let me cry or make me a cup of tea. (S8, p.127)

Other participants reported positive experiences of openly grieving in front of people they supported, which they felt normalised the emotional nature of bereavement and gave PWID permission to grieve:

> Recently I got very upset when I heard one of the women had died. Her peer saw me crying and came to me and started to cry too. On reflection I thought my crying was a good thing and gave credence to her emotions even if she was mimicking my behavior [sic] it was right for her. (S8, p.122)

Another participant experienced some shame in accepting support from someone they supported during a shared bereavement: “You can sort of go to him and tell him anything. I know we shouldn’t!” (S2, p.190). This shame appeared to relate to a belief amongst participants that they were expected to maintain a solely occupational relationship within their roles: “We were supposed to distance ourselves but you can’t. If you did, well you couldn’t really care could you? You’re too involved with people to be distant. I’m human … I can’t hide behind a professional mask.” (S9, p.225). Although participants felt that this was incongruous with their caring role, this expectation left them reluctant to seek support from managers for their grieving for fear of negative evaluation: “You are expected to draw a line around it. To be professional. To have no emotions or feelings … to have a stiff upper lip.” (S9, p.225).

This belief that participants’ relationships with the deceased went unrecognised by management was supported by the perceived insensitivity shown by participants’ organisations after a death: “It’s known as a void! An empty bed that needs to be paid for … It would have been nice though if we had had more time to get used to him not being there.” (S9, p.225).

Although participants felt unsupported in managing the death of people they supported, experience lessened the impact: “It does get easier but you never forget” (S2, p.189). One participant, who had been reluctant to get support after a death, reported that she would be more likely to do so now she knew how the grieving process had affected her:

> I think maybe I could have talked to someone but I felt … they’ll say “She’s a right moron” … I’m OK with it but … if somebody had … said “Would you like to talk to somebody?” I’d say yeah, definitely I would. (S7, p.592)

This theme highlights the disparity between participants’ personal experiences following the death of someone they support, and the expectations that they perceived from management to remain professional and unaffected by the death.

3.4. Overarching theme – A “cautious silence”: The taboo of death

The preceding three themes offer a line of argument synthesis (Noblit & Hare, 1988) of the papers included in the review. This overarching theme offers an interpretation of what can be learnt from the 13 papers as a whole, by examining and integrating each study through a process of translation (Noblit & Hare, 1988; Pope et al., 2007).

The synthesis revealed a “cautious silence” (S1, p.253) surrounding death within participants’ organisations. This appeared to relate to death being a taboo topic, which might be too difficult to explore with PWID: “There’s a huge lack of awareness and understanding across the whole of the organization really about the impact of loss and bereavement for people with ID” (S7, p.592). However, it was very apparent from the studies that PWID experienced frequent losses: “When I stop and think how many residents [have died] … How many have gone, someone’s always going.” (S11, p.988).

Organisational silence meant participants experienced uncertainty about whether to talk to PWID about death, how to do this, and whether they were doing it correctly. This was also evident in their approach to supporting PWID through their death, where their commitment to doing so was often challenged by a lack of certainty and knowledge of how to do this. The taboo of death meant that organisations seemed to lack an agreed approach or framework for dealing with death, dying, and bereavement. This created inconsistencies between staff, which often depended whether or not they had encountered death within their role. Despite this, most participants appeared to be relatively good at supporting people with issues of death, dying, and bereavement, but lacked confidence in their abilities to do in the absence of feedback. The following excerpt acknowledges this: “These are skills; these are human skills we’re going to be trying to develop in staff. Like, most staff have them, it’s just a matter of finding them and developing them.” (S7, p.593).

This taboo also affected how participants managed their own response to death, dying, and bereavement in their workplace. The silence around death appeared to interact with a lack of recognition of the bonds that participants had with those they support. This created a culture of silence, where participants felt unable to discuss the impact of a person’s death with their managers. This reluctance to seek support, however, appeared to further reinforce the silence, because participants were “getting on with it” and the impact of death was therefore minimised.

4. Discussion

This metasynthesis aimed to explore the experiences of staff working in ID settings in supporting PWID with issues of death, dying, and bereavement. The findings indicated that the taboo of death, which is common to many (Doka & Davidson, 1998), was pervasive within the ID services represented in these studies, despite the high frequency of deaths that participants alluded to. There was considerable uncertainty amongst participants about talking to PWID about issues of death, dying, and bereavement. This was seen as a subject that nobody wanted to talk about. Yet for staff, it was an issue they had to navigate their way through one way or another. Consequently, supporting PWID with issues of death, dying, and bereavement was approached inconsistently and with considerable anxiety by participants.

While many participants worked hard to improvise, for example, using their personal experiences of grief as a guide, their belief that they lacked appropriate knowledge, training, policies, and resources with which to confidently tackle this subject prevailed. This supports findings from MacHale, McEvoy and Tierney (2009), who found staff to lack confidence in their ability to offer support PWID with bereavements. Nevertheless, participants who attempted to address this issue appeared to be relatively skilled at doing so. This was illustrated by the range of strategies employed. However, they doubted their abilities due to a lack of appropriate feedback.

The Care Quality Commission (CQC), who are responsible for the independent regulation of English health and social care (CQC, 2015), have recently published guidelines (CQC, 2013) advising on the importance of supervision for all staff suppporting PWID. This follows the 2011 care failings at Winterbourne View (see Department of Health, 2012) which, amongst other issues, highlighted devastating consequences of staff being inadequately managed, trained, and supported. While this is an extreme example, it highlights the importance of effective supervision for all staff involved in supporting PWID. The CQC guidelines (CQC, 2013) therefore argue that supervision and appraisal are imperative in ensuring staff receive feedback on their performance and skills so they can develop professionally and personally.

Some participants in the studies reviewed held preconceptions about PWIDs' abilities to understand and tolerate information related to death, which sometimes inhibited their openness. These beliefs are consistent with the contested reports that PWID are incapable of experiencing grief (Hollins & Kloeppel, 1989) and also support the suggestion that PWID are often protected from knowing about death (Hollins & Tuffrey-Wijne, 2010). McRitchie et al. (2014) found that the PWID in their study wanted to be involved in discussions about death, dying, and bereavement; they argued for the importance of systemic support for adults with ID who are grieving. However the attitudes and assumptions shown by some participants in this metasynthesis suggest that too little is being done within ID services to educate staff of the benefits of supporting PWID to develop their knowledge, or in providing guidance about how to do so.

While not supporting PWID to know about death, dying, and bereavement was only reported by a minority of participants, it suggests that some participants still held attitudes towards PWID as "eternal children," which is a concept first proposed by Wolfensberger (1972). This supports an argument by Mee (2012), who posits that although the eternal child attitude towards PWID is generally seen as out-dated, it often still exists on an unconscious level. Furthermore, the protection of PWID from issues of death, dying, and bereavement has the potential to promote disenfranchised grief (Doka, 1989), which in turn may prevent PWID from learning about death. Attig (2004) has argued that such disenfranchisement discourages the bereaved from grieving and invalidates any such response.

Furthermore, death secrecy within services means that PWID are unlikely to witness the precursors of death that could help them to understand the reasons for a deceased person's absence. Corr, Nabe and Corr (2009) suggested that a child's exposure to knowing about death as they develop influences and promotes the development of their concept of death. It could therefore be argued that observation of the life cycle through exposure to, or knowledge of, death and dying is critical if PWID are to develop their understanding of death. This is supported by evidence suggesting PWID understand death better when supported by concrete experiences (Dusart, 2008; Harper & Wadsworth, 1993). A lack of education due to overt protection from death may even reinforce the assumptions made by some participants in this metasynthesis, that PWID are unable to understand death or experience grief.

Another important finding was participants' commitment to supporting PWID through their own death at home, despite the considerable anxiety they experienced due to a lack of knowledge and training of how to do so. This supports findings by Ryan, Guerin, Dodd and McEvoy (2011). This commitment emphasized the importance of the relationship between staff and people they support, in that participants felt that hospital care would not adequately meet the person's individual needs. This is consistent with findings by Li and Ng (2008), which indicated that the in-depth knowledge that staff had of PWID they support was critical in providing end-of-life care.

"Dying in place" (British Psychological Society [BPS], 2015), which replaced the term "ageing in place" (Janicki, McCallion & Dalton, 2000) is a term which has been used to refer to the requirement for ID services to adapt to accommodate PWID who have developed dementia (Watchman, 2003). However, this can equally be applied to any such end-of-life issue. For this to be successful, ID services need a more open culture around death, the appropriate equipment and resources to prevent unnecessary admission to hospital, and staff training in the provision of palliative care. It was acknowledged that hospital care was sometimes inevitable, for example, when specialist medical support is required. In these circumstances, staff require support with the emotional impact of this transition, including feelings of anger and failure.

Participants' efforts to support PWID with bereavements were often influenced by their own grieving for the deceased. This grief was a consequence of the longevity and "embedded" nature of their relationship with the person, which is consistent with Ryan et al.'s (2011) findings that grieving was influenced by the length of time staff had known the PWID. Participants in the reviewed studies highlighted the disparity between the importance *they* placed on their relationships with people they supported and the perceived expectation by managers to maintain a professional relationship. Many participants were therefore reluctant to grieve for fear of negative evaluation from managers, or because of a perceived expectation to prioritise supporting the PWID's grieving.

This inability to mourn openly and resulting lack of acknowledgement from management for their grief suggests that staff were also susceptible to disenfranchised grief (Doka, 1989). Staff's disenfranchised grieving, however, limits the potential for the grieving process to be modelled to PWID. This could in turn reinforce PWID's disenfranchised grief. This further supports the importance of clinical supervision, as discussed above. In addition to providing staff with feedback on their performance, such support provides a forum in which to explore their own emotional reactions to their role (CQC, 2013). A more open culture within ID services about death and the importance of the relationship could therefore be beneficial to PWID and staff in managing the implications of death, dying, and bereavement.

4.1. Clinical implications

The findings of this metasynthesis have highlighted several implications for clinical practice. Firstly it has identified a need for training for paid staff on the issues related to supporting PWID with death, dying, and bereavement. Training has been shown to improve staff's confidence in supporting bereaved PWID (Reynolds, Guerin, McEvoy & Dodd, 2008). The findings from this metasynthesis suggest that such training would include information about PWIDs' understanding of the concept of death, means of discussing death with them, how to recognise and support PWID's grief, information on providing end-of-life care, and how staff could recognise and manage their own grief. Such training could improve staff's confidence in supporting PWID with all issues related to death, dying, and bereavement.

Clinical psychologists are skilled applying psychological theory to a range of difficulties experienced within services and can offer training to staff teams for specific issues (Jones & Hartley, 2015). Clinical psychologists and other members of community ID teams would therefore be well-placed to develop and deliver death, dying, and bereavement training to staff from ID organisations to improve their confidence in supporting PWID.

Such training could be supported by the availability of appropriate resources to support staff in facilitating discussions about death with the people they support. For example, Levitan, Dodd, Boulter and Mackey (2012a; 2012b; 2012c) produced three accessible guides for supporting PWID with issues related to death, dying, and bereavement.

Staff may also benefit from space for reflection, validation and feedback within their roles via supervision, as advocated by the CQC (2013) in their guidance on supervision for staff supporting PWID. While this could be facilitated by service managers, it could also be supported by clinical psychologists, who are skilled in offering supervision and consultation to other support providers (Jones & Hartley, 2015). In particular, having a reflective debrief following a person's death may help staff to feel supported in their own grieving. This may increase the quality of support they can offer to PWID. It should be acknowledged that provision of a debrief by a clinical psychologist may not be part of a service level agreement between a community ID team and third sector ID organisations. This highlights a potential void between the need and availability of commissioned support.

Finally, the findings indicate the requirement for formal policies and procedures to be developed regarding death, dying, and bereavement within organisations providing support to PWID. Such guidelines could incorporate the recommendations above as part of their protocol for managing death, dying, and bereavement within their service, and could be guided by National Institute of Health and Care Excellence (NICE) commissioning guidance on end-of-life care in England (NICE, 2011).

4.2. Limitations

The purpose of this review was to identify examples of salient issues affecting staff supporting adults with ID, which are not intended to be generalised. It should not be assumed that these issues are salient for all organisations supporting PWID. Therefore it is important to establish whether they are represented within an individual service before any changes are made or specialist input is offered. However, it is also important to be aware of the taboo culture related to death, which appears to exist on a societal level; this may influence services' willingness to accept support. Findings may represent issues which are not generalisable to other nations and cultures from those included in the review.

It should also be noted, as described in section 2.3, that some papers included in the metasynthesis were of poorer quality than others, according to the CASP ratings assigned. However, it was ensured that the lower rated papers (e.g. S3 and S4) were used for enhancement of the themes developed from stronger papers. Nevertheless, this review offers the first known systematic review specifically focusing on the experiences of staff from ID settings in supporting PWID with death, dying, and bereavement.

4.3. Future research

This metasynthesis highlights several areas which warrant further research. The grief experienced by participants in these studies warrants further exploration. For example, qualitatively exploring the experiences of support received by staff following the death of a PWID would provide further information on the current limitations of this highlighted by this review.

Research exploring the impact of training programmes (as recommended in section 4.1) on staff's attitudes towards supporting PWID with death, dying, and bereavement would also be useful in providing evidence for the importance of a more open death culture in services. This could be done using pre- and post-training measures, however, it is worth noting staff satisfaction and learning reported following training does not always translate into clinical practice, as found by Smith (2011) who explored the impact of brief therapy training on social workers supporting PWID. It would therefore be of merit to follow this up with a qualitative exploration of staff attitudes in the months following training.

Although research exists which directly explores PWIDs' experiences of being supported with issues of death, dying, and bereavement (e.g. Forrester-Jones, 2013; Gilrane-McGarry & Taggart, 2007; McEvoy et al., 2012; McRitchie et al., 2014), this is still somewhat limited, perhaps due to the perceived difficulties of involving PWID in research (see Kiernan, 1999; Rodgers, 1999). However, Tuffrey-Wijne and colleagues (e.g. Tuffrey-Wijne, Bernal, Butler, Hollins & Curfs, 2007) have used the Nominal Group Technique (Delbecq, Van de Ven & Gustafson, 1975) to explore the perspectives of PWID in a meaningful and useful way. Further research into PWIDs' knowledge of, and experiences being supported with, issues of death, dying, and bereavement, perhaps using this methodology, are certainly warranted.

4.5. Conclusions

This metasynthesis provides a systematic review of the available research regarding the experiences of staff supporting PWID with issues of death, dying, and bereavement. It has highlighted that the societal taboo of death exists within ID settings despite the frequent bereavements experienced by PWID. Staff uncertainty about how best to support PWID to understand death and to grieve, as well as supporting them through their death, was found to go unrecognised by management. Consequently, staff felt unsupported in providing this care, further exacerbating their lack of confidence. The findings highlight the potential for this culture of silence to invite disenfranchised grief for both PWID and staff. Nonetheless, the review revealed a commitment and desire from staff to support PWID. With appropriate support and training it is possible that this silence can be eradicated.

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Table 1

Breaking Down the Research Question, Informed by SPIDER Tool

SPIDER heading	Search topics
S – Sample	Learning disability staff People with learning disabilities
PI – Phenomenon of Interest	Issues related to death and dying
D & R – Design and Research Type	Qualitative research

Table 2

Free Search Terms

	Domain	**Free search terms**
S – Sample (1)	Learning disability staff	Direct care staff OR Staff OR Carer* OR Caregiver* OR Professional Carer* OR Support worker* OR Care assistant* OR Care staff OR Paid carer
S – Sample (2)	People with learning disabilities	Learning disabilit* OR Intellectual disabilit* OR Mental* retard* OR Mental* handicap* OR Down* syndrome OR Intellectual impairment* OR Developmental disabilit*
PI – Phenomenon of Interest	Issues related to death and dying	Death OR Dying OR Die OR Bereav* OR Mourn* OR Loss OR Grief OR Griev* OR End of life OR Palliative OR Terminal
D & R – Design and Research Type	Qualitative research	Qualitative OR Interview* OR Focus group* OR Phenomeno* OR Thematic analysis OR Grounded theory OR Narrative analysis OR Interpretative phenomenological analysis OR IPA OR Discourse analysis OR Content analysis OR Qualitative analysis OR Conversation analysis

Table 3

Subject Headings and Thesaurus Terms

Domain		**Database**	**Database Subject Terms**
S - Sample	Learning disability staff	MEDLINE MESH Headings	(MH "Caregivers") OR (MH "Disabled Persons+") OR (MH "Allied Health Personnel+") OR (MH "Nursing Staff+")
		PsychInfo Thesaurus Terms	DE "Independent Living Programs" OR DE "Palliative Care" OR DE "Home Care Personnel" OR DE "Paraprofessional Personnel" OR DE "Home Care Personnel" OR DE "Allied Health Personnel" OR DE "Caregivers" OR DE "Elder Care" OR DE "Home Care"
		Academic Search Complete	DE “CAREGIVERS”
		CINAHL	(MH "Caregivers") OR (MH "Allied Health Personnel+") OR (MH "Health Personnel+")
		EMBASE	exp caregiver/
		Web of Science	*Function not available on this database.*
	People with learning disabilities	MEDLINE MESH Headings	(MH "Intellectual Disability+") OR (MH "Mentally Disabled Persons") OR (MH "Developmental Disabilities")
		PsychInfo Thesaurus Terms	(DE "Intellectual Development Disorder") OR (DE "Down's Syndrome")
		Academic Search Complete	(((DE "LEARNING disabilities" OR DE "NONVERBAL learning disabilities") AND (DE "LEARNING disabilities research" OR DE "LEARNING disabled persons")) OR (DE "MENTAL retardation")) OR (DE "DOWN syndrome")

		CINAHL	(MH "Intellectual Disability+") OR (MH "Developmental Disabilities") OR (MH "Down Syndrome")
		EMBASE	exp developmental disorder/ OR exp intellectual impairment/ OR exp learning disorder/ OR exp Down syndrome/
		Web of Science	*Function not available on this database.*
PI – Phenomenon of Interest	Issues related to death and dying	MEDLINE MESH Headings	(MH "Bereavement+") OR (MH "Grief") OR (MH "Death+") OR (MH "Parental Death+") OR (MH "Attitude to Death") OR (MH "Palliative Care") OR (MH "Terminal Care+") OR (MH "Terminally Ill")
		PsychInfo Thesaurus Terms	(((DE "Bereavement" OR DE "Grief") OR (DE "Death and Dying" OR DE "Parental Death")) OR DE "Death Anxiety" OR DE "Death Attitudes" OR DE "Death Education" OR DE "Death Rites" OR DE "Palliative Care")) OR (DE "Terminally Ill Patients")
		Academic Search Complete	((DE "BEREAVEMENT" OR DE "BEREAVEMENT -- Psychological aspects" OR DE "GRIEF") OR DE "DEATH" OR "PARENTS -- Death" OR DE "PLACE of death" OR DE "SUDDEN death" OR (DE "LOSS (Psychology)") OR (DE "PALLIATIVE treatment") OR (DE "TERMINAL care")
		CINAHL	(MH "Palliative Care") OR (MH "Terminal Care+") OR (MH "Bereavement+") OR (MH "Grief+") OR (MH "Personal Loss") OR (MH "Complicated Grief") OR (MH "Death+")
		EMBASE	exp bereavement/ OR exp grief/ OR exp death/ or exp attitude to death/ or exp mourning/ or exp palliative nursing/ or exp terminal care/
		Web of Science	*Function not available on this database.*

D & R – Design and Research Type	Qualitative research	MEDLINE MESH Headings	(MH "Qualitative Research")
		PsychInfo Thesaurus Terms	DE "Content Analysis" OR DE "Grounded Theory" OR DE "Interviews" OR DE "Interview Schedules" OR DE "Qualitative Research"
		Academic Search Complete	DE "INTERVIEWING" OR DE "SOCIAL sciences -- Fieldwork" OR DE "QUALITATIVE research" OR DE "CONVERSATION analysis"
		CINAHL	MH "Qualitative Studies+") OR (MH "Data Analysis+") OR (MH "Focus Groups") OR (MH "Interviews+") OR (MH "Narratives")
		EMBASE	exp methodology/ or exp grounded theory/ or exp qualitative research/or exp qualitative analysis/
		Web of Science	*Function not available on this database.*

Table 4

Key characteristics of studies included in metasynthesis

Study number	**Author**	**Year**	**Aim/goal/research question of study**	**Country**	**Overall sample size**	**Sample that can be included in metasynthesis (according to inclusion / exclusion criteria**	**Age range of participants included in metasynthesis**	**Gender of participants included in metasynthesis**	**Roles/settings of participants including in metasynthesis**	**Method of data collection for included participants**	**Method of qualitative data analysis for included participants**
S1	Forrester-Jones	2013	To understand how intellectual disability services manage the planning of PWID's funerals; to understand what support these services offer to PWID/staff/relatives regarding funerals and grief; to explore which elements of funerals are important to PWID.	England	63	38	Not stated	Not stated	ID residential or assessment service managers (including social services, NHS, private and voluntary services)	Qualitative questionnaire	Thematic content analysis
S2	Handley and Hutchinson	2013	To understand how staff support PWID with bereavement and what influences the decisions they make during this process.	England	11	4	Does not specify age of participants included in metasynthesis, but age range of all participants is 47-79 years	Female	Residential service staff	Semi-structured interviews	Interpretative phenomenological analysis

S3	Hoover, Markell and Wagner	2005	To explore residential care providers' views regarding how they support PWID with death and grieving.	USA	57	57	31-49 years	43 females, 14 males	Residential service staff	Survey with qualitative responses	Does not state specific method, but appears to use a thematic content analysis
S4	Kirkendall and Waldrop	2013	To describe the perspectives of staff from a community residence for PWID regarding end-of-life.	USA	8	8	24-64 years	6 females, 2 males	Frontline workers, managers and registered nurses in a community residential service	Semi-structured interviews	Grounded theory techniques
S5	McCarron, McCallion, Fahey-McCarthy and Connaire	2010	To understand the concerns of staff in ID services and palliative care services in supporting PWID and advanced dementia.	Ireland	57*	50	Not stated	Not stated	Exact job role not stated, but described as providing "direct care to at least one person with ID and advanced dementia" (p.144).	Focus groups	Thematic analysis

S6	McCarron, McCallion, Fahey-McCarthy and Connaire	2011	To explore the role/timing of palliative care interventions for PWID and advanced dementia.	Ireland	57*	50	Not stated	Does not state gender of those included in metasynthesis, however of the total 57 participants, 53 were female, 4 were male.	Overall sample included nursing staff, care workers, doctors and social worker. It is not clear which job roles applied to those participants included in metasynthesis (i.e. staff from ID services.)	Focus groups	Qualitative content analysis
S7	McEvoy, Guerin, Dodd and Hillery	2010	To describe how staff in a large voluntary sector service experienced supporting PWID with bereavements.	Ireland	24	24	24-57 years old	17 females, 7 males	Administrative, clinical, nursing and frontline staff from day and residential services for people with intellectual disabilities.	Focus groups	Content analysis
S8	Morgan and McEvoy	2014	To understand staff perceptions of how older female PWID living in residential care are affected by bereavement and how these people respond and cope with grief.	Ireland	10	10	28-56 years old	10 females	Staff working in a centre providing residential, nursing and day services for older women with IDs.	Semi-structured interviews	Interpretative phenomenological analysis

S9	Todd	2013	To understand how staff interpret/respond to the death of PWID; to understand how this is shaped by staff members' values.	England and Wales	22	22	Not stated	Not stated	Staff from ID service providers offering residential services to PWID	Interviews	Thematic analysis
S10	Tuffrey-Wijne et al.	2013	To explore whether, and how, stakeholders disclose news of life-limiting illness and death to PWID, and whether there are circumstances where disclosure may cause harm. The overall aim of this was to develop guidelines regarding disclosure decisions.	England	109	26	Not stated	Not stated	Professionals in health or social care services specialising in intellectual disabilities, with experience supporting a client with end-of-life care.	Focus groups	Content analysis, following Grounded Theory procedures
S11	Wiese, Dew, Stancliffe, Howarth and Balandin	2013	To explore how staff in community living environments engaged with PWID regarding dying/death.	Australia	33#	33	19-75 years old	28 females, 5 males.	Community living staff, including direct care and middle management staff	Phase 1 – focus groups; Phase 2 – interviews	Guided by Grounded theory techniques

S12	Wiese, Stancliffe, Balandin, Howarth and Dew	2012	To describe the issues that staff supporting PWID experience during end-of-life care.	Australia	33#	33	Does not state age range, but mean age of 44	28 females, 5 males	Community living staff, including direct care and middle management staff	Phase 1 – focus groups; Phase 2 – interviews	Guided by Grounded theory techniques
S13	Wiese, Stancliffe, Dew, Balandin and Howarth	2014	To explore how community living staff engaged and supported PWID to understand and know about death and dying.	Australia	22	22	21-75 years old	20 females, 2 males	Community living staff, including direct care and middle management staff	Phase 1 – focus groups; Phase 2 – interviews	Guided by Grounded theory techniques

* These studies use the same group of participants.

#These studies use the same group of participants.

Table 5
Quality Appraisal of Selected Studies

CASP question	**Study Number**												
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**
1. Was there a clear statement of the aims of the research? (Y/N)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
2. Is qualitative methodology appropriate? (Y/N)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
3. Was the research design appropriate to address the aims of the research? (1-3)	1	3	1	1	3	3	3	3	3	1	3	3	3
4. Was the recruitment strategy appropriate to the aims of the research? (1-3)	3	2	3	2	2	3	3	3	3	3	3	3	3
5. Was the data collected in a way that addressed the research issue? (1-3)	2	2	2	1	3	2	3	3	3	3	3	3	3
6. Has the relationship between the researcher and participants been adequately considered? (1-3)	1	2	1	1	1	1	1	2	3	2	2	3	3
7. Have ethical issues been taken into consideration? (1-3)	3	2	1	1	2	2	1	3	2	3	3	3	3
8. Was the data analysis sufficiently rigorous? (1-3)	2	3	2	1	2	2	3	3	3	3	3	3	3
9. Is there a clear statement of findings? (1-3)	3	3	2	1	2	2	3	3	3	3	3	3	3
10. How valuable is the research? (1-3)	3	3	2	1	3	2	2	3	3	3	3	3	3
Total CASP score (possible range 8-24)	**18**	**20**	**14**	**9**	**18**	**17**	**19**	**23**	**23**	**21**	**23**	**24**	**24**

Table 6

Contribution of each study to the metasynthesis themes

Theme		S1	S2	S3*	S4*	S5	S6	S7	S8	S9	S10	S11	S12	S13
1	Talking about death is hard: Negotiating uncertainty in death, dying, and bereavement	×	×	×	×	×		×	×	×	×	×	×	×
2	The commitment to promoting a "good death"				×	×	×			×			×	
3	The grief behind the "professional mask"		×					×	×	×			×	
Overarching theme	A "cautious silence": The taboo of death	×	×	×	×	×	×	×	×	×	×	×	×	×

*Note: The contribution of S3 and S4, which had the lowest CASP scores, was for enhancement only.

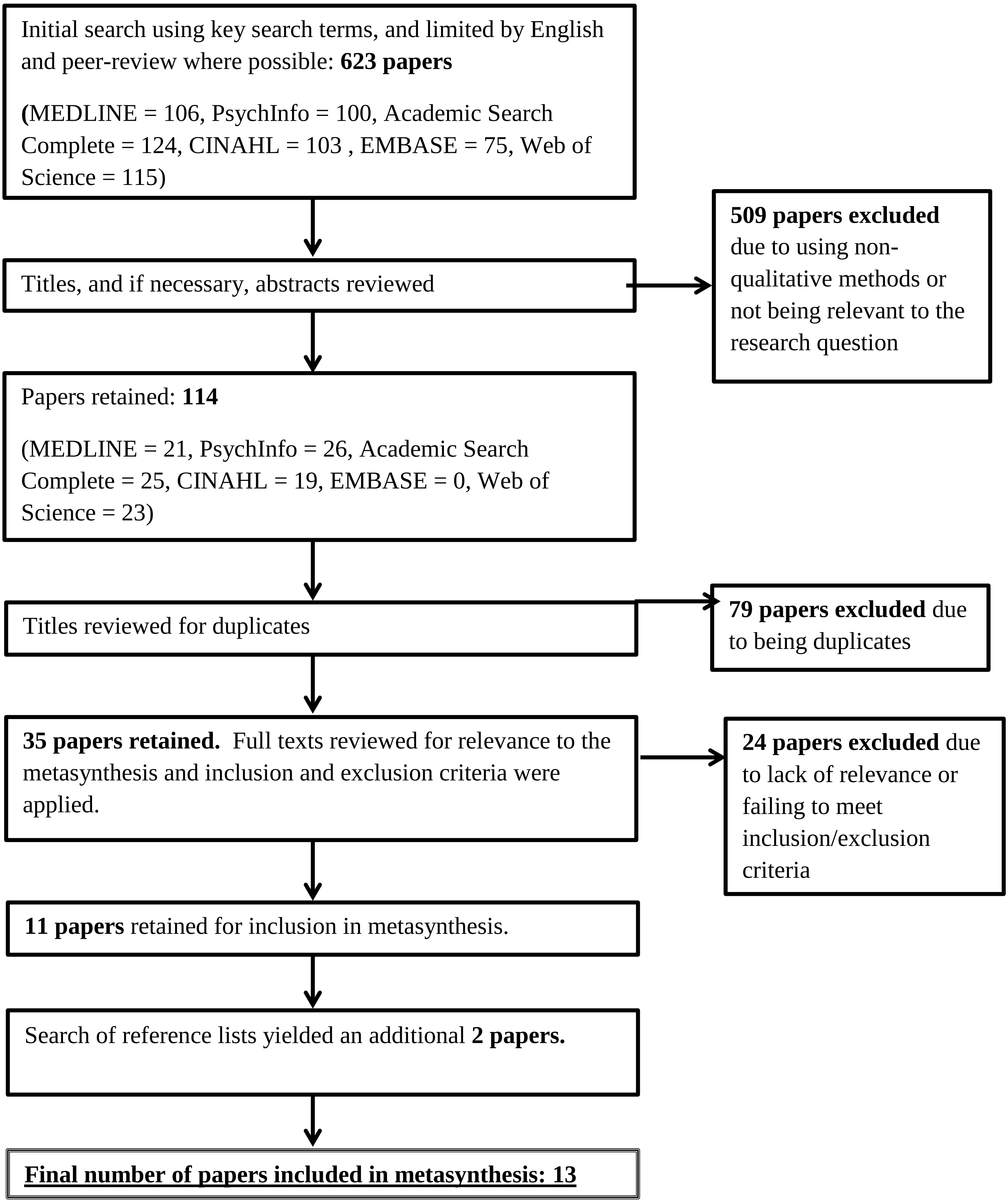

Figure 1
Flow diagram of systematic search strategy

Appendix 1-A

Author Guidelines

RESEARCH IN DEVELOPMENTAL DISABILITIES

AUTHOR INFORMATION PACK

TABLE OF CONTENTS

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DESCRIPTION

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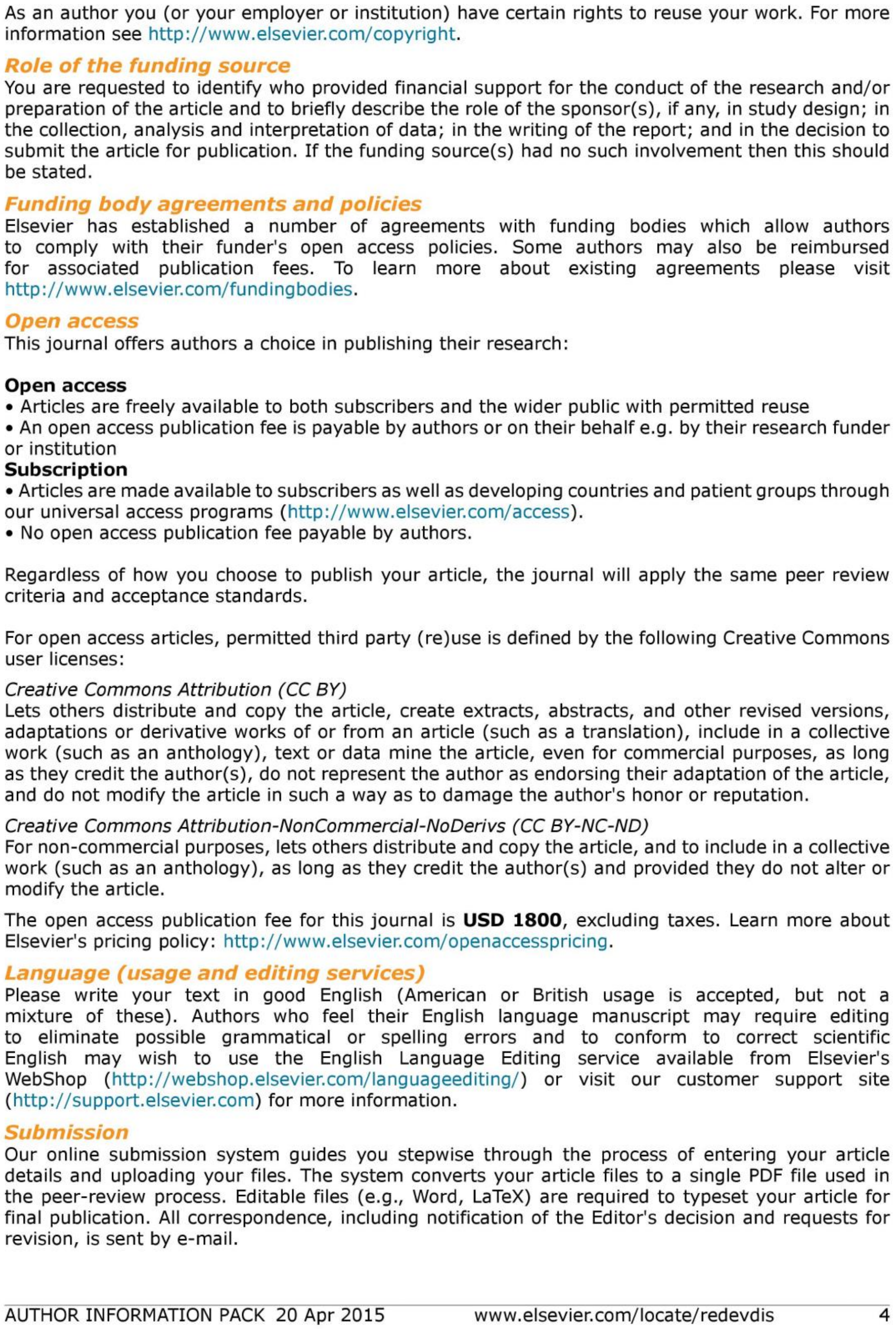

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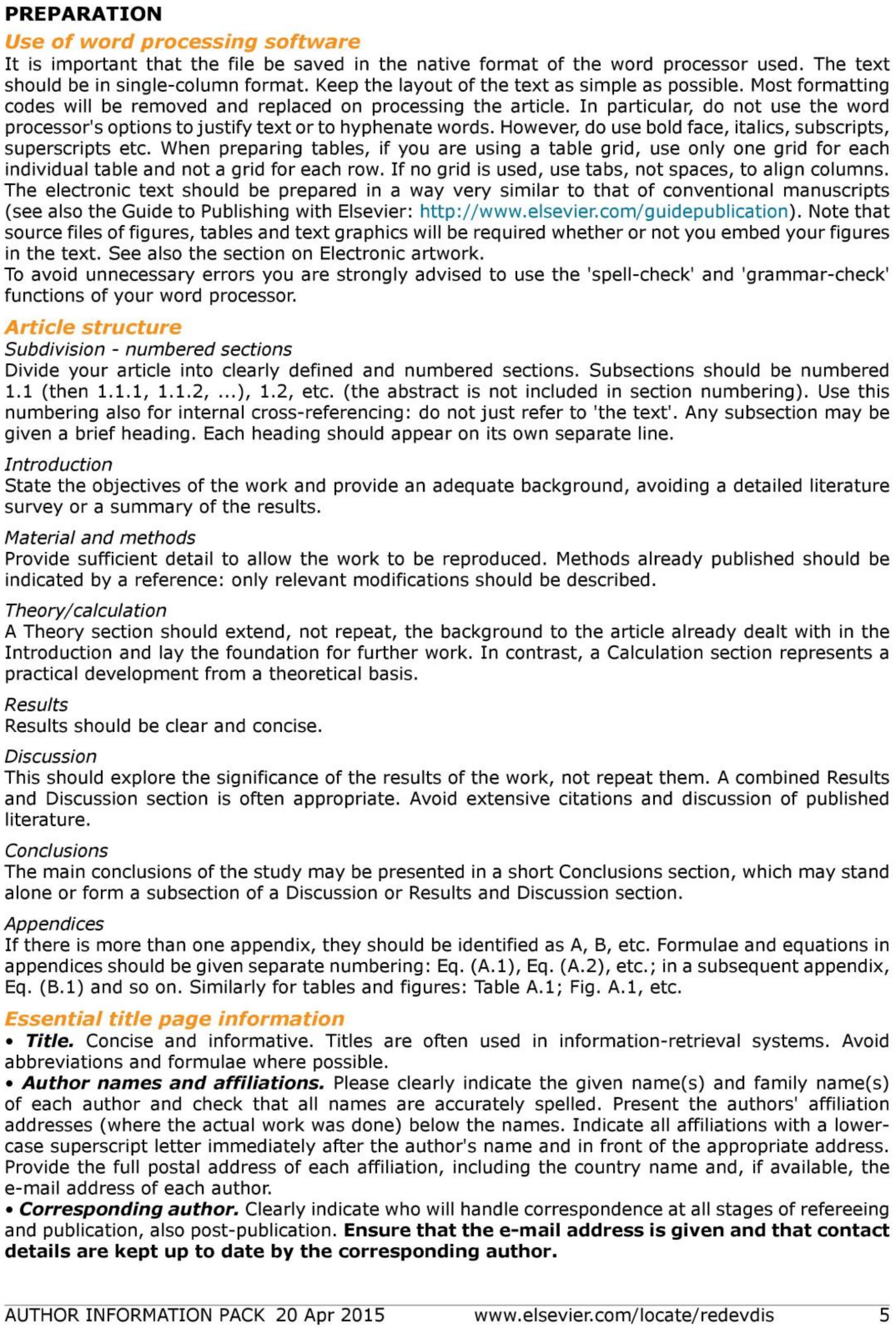

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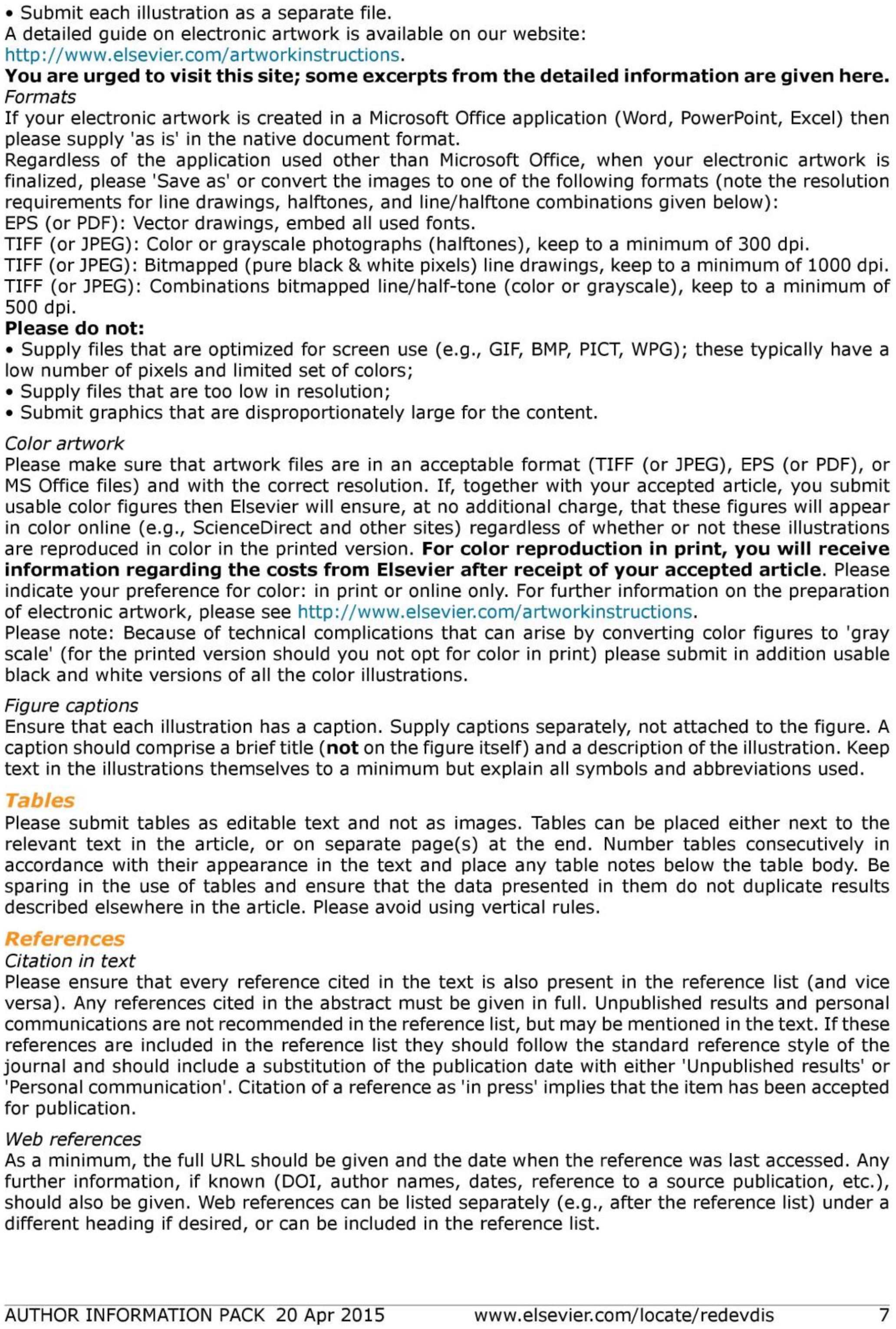

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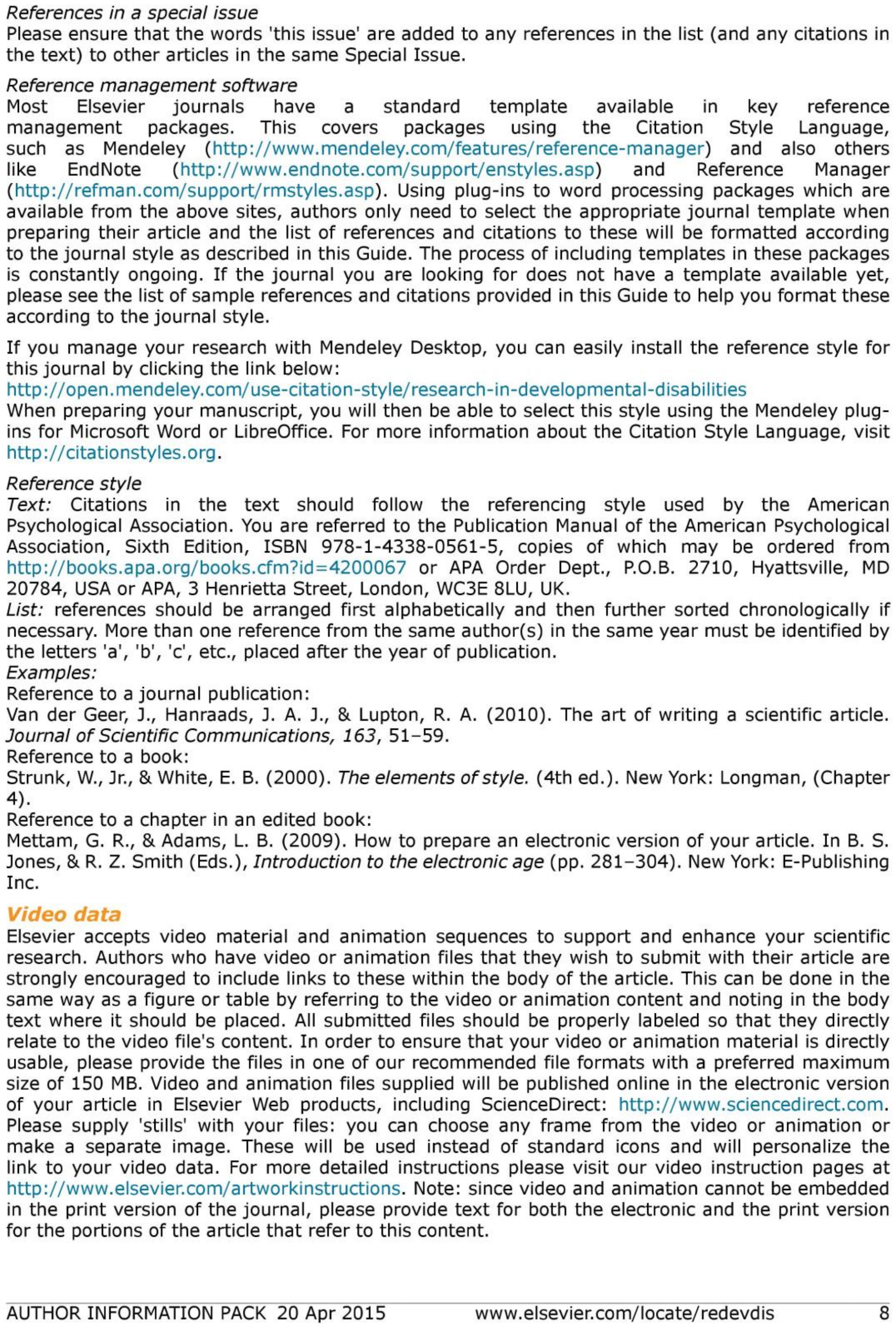

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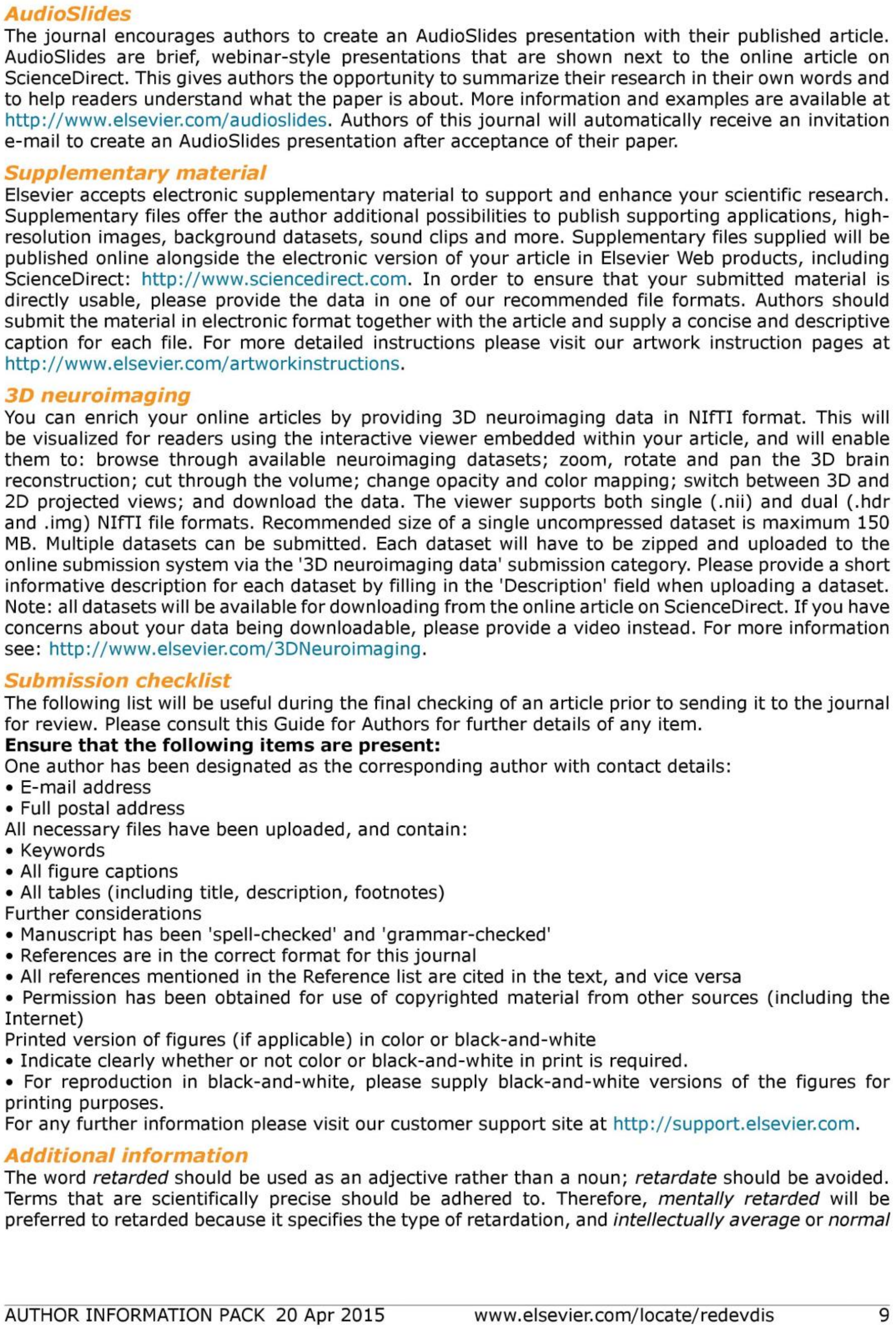

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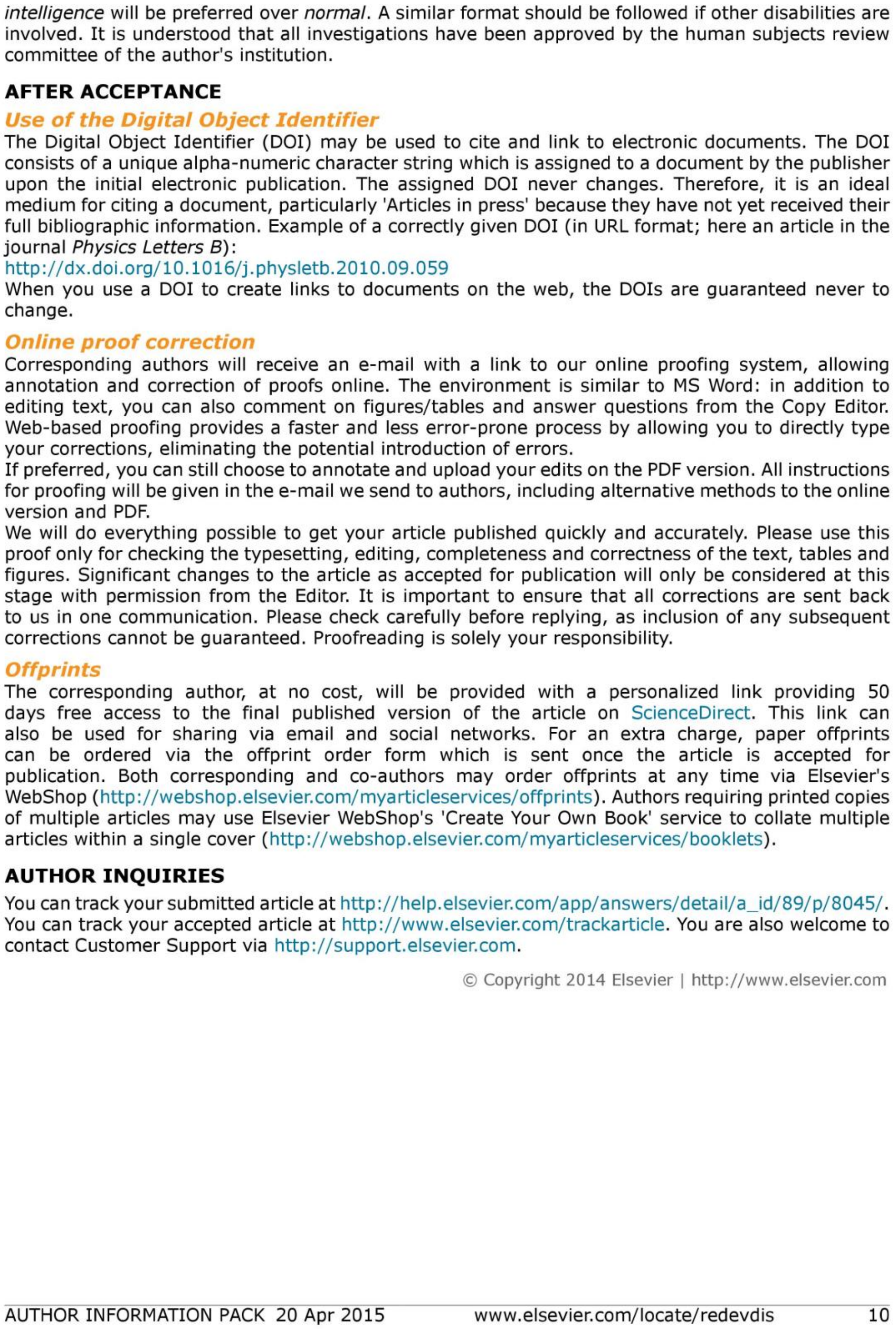

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Appendix 1-B

Example of how data from S2 and S7 contributed to Theme 3, "The grief behind the 'professional mask'"

Study	Original Author's Theme Title	Original Author's Interpretations	Representative Quotes	Metaphors and/or Interesting Phrases	My Comments and Interpretations
S2	Factors making the experience difficult for carers (theme 1)	• Experience is emotional. • Residential carers often grieving for the same loss or reminded of the pain of personal losses. Residential carers saw themselves as embedded in the lives of PWID; the emotional resonance revealing that the experience was deemed so much more than 'work'. • Uncertainty about how to support PWID following bereavement. • Impact of multiple and often conflicting demands. Residential carers spoke of the need to manage ongoing duties whilst coping with the emotional impact. • Expressed regret or guilt surrounding the juggling of these demands and resigned to a sense of meeting the needs of one party to the detriment of another. • Multiple demands, combined with uncertainty about what to do or say, left carers feeling unsure about where to start	It does get easier but you never forget…because it's not like working in a shop or a factory, you know, when you're actually involved with people's lives and their day to day lifestyle, you know, it was really really hard. (Residential carer, interview 11)	• Not like working in a shop or a factory • Involved with people's lives • Embedded in lives of PWID • Multiple and conflicting demands. Juggling.	• Supporting PWID with bereavement is inextricably linked to own experience of loss as staff member. Factory/shop metaphor – you can't switch off the fact you are embedded within the PWID's life – there is a relationship. More than just a job – this relationship makes it so? • Sense of not being able to give appropriate time to PWID because of duties of job. Can't be everything to everyone, so something has to give.

Factors that helped carers (theme 2)	• Despite demands, carers noted the benefits of the ongoing care needs of PWID – raison d’être for carer – promote adjustment to life without the deceased and facilitating grieving process. • Support a mutual and reciprocal interaction between carers and PWID. • Shifting boundaries between carer and PWID – experienced distress together as equals, with the “disability” itself becoming less apparent.	“When people are upset he just seems to know and then he’ll go and try to, sort of, comfort people. And then he won’t try to bite at all; and then he will actually sit with you and you can sort of go to him and tell him anything’. I know we shouldn’t!” (Residential Carer, interview 10)	• Raison d’être • Adjustment • Mutual, reciprocal support • Shifting boundaries • Equals • I know we shouldn’t!	• Caring responsibilities helped staff to adjust/grieve – likely to impact on support for clients too. • Death brings more equality – both parties need to grieve – so can support each other to do so. • Bringing them together with a common experience – dissipates difference between someone with disability or not. • I know we shouldn’t – is the carer’s need usually denied? Role of a carer is to care, not to receive care – some shame in accepting care from person you care for?

Support for carers (theme 5)	• Important for carers to have support when supporting PWID with bereavement. • Carers thought that providing bereavement support to clients was something they had to manage themselves, as didn’t know where to access help, felt guilty for doing so, and felt that their extensive knowledge of the PWID left them better able to provide bereavement support than an outside source. • Carers wanted access to training and information for themselves and families. • Carers emphasized the need for empathic line management – emotional impact following bereavement wasn’t always acknowledged.	*No quotes from ID staff*	• Bereavement support something to manage ourselves. • Guilt (for accessing support)	• The difficult nature of supporting PWID with bereavement means they can’t always do it alone – need to call on other sources. • This is something that is not often acknowledged by line managers, but also carers seem to “carry the load” themselves, feeling that they know the person best and because of guilt for asking for help. • Carers desire for training – feel bad for not being able to support PWID adequately?

	From discussion section of paper	• Bereavement support involves juggling multiple demands, to manage the impact of personal grief and make difficult decisions despite extensive uncertainties. • Bereavement support has emotional resonance for carers. Guilt and regret that meeting one person's needs is at the detriment of another person's. • Mutuality of support during bereavement – diluted disability and care hierarchy and a renegotiation of the relationship with the PWID without the deceased. • Carers resigned to coping alone, despite saying they needed support. • Carer emotionality impacts on what is offered to PWID. • Tension between being embedded in PWIDs lives and the employment structures which don't account for the inevitable emotional impact of their work. • Decisions impacted on by the needs of the carers, but also by the nature of their unique relationship with the PWID	n/a	n/a	• Emotional impact on carers influences the support that PWID have in managing their grief – an unrecognised need because carers are good at keeping on going and handling things themselves – is this a product of having to juggle demands – this is a role where personal reflection/support time isn't given adequate space? Staff are used to plodding along. • Can plod along and handle it as long as it matches own personal expectations of grief – then don't know what to do and leads to guilt. • No permission from employment structure to care for self – lack of acknowledgement that support for PWID depends on staff feeling they are supported. Support structure inadequate – is this to do with it being a taboo subject that nobody talks about?
S7	Staff experiences of supporting people with ID (topic 2) – subsection of theme: Staff members' own reaction	• First theme - Staff members' own reaction to bereavement at a personal and professional level. • Personal level – bereavements experienced by service users can have a direct emotional effect on staff themselves. • This reaction was associated with the nature of the interpersonal relationships	• Some of the staff can be absolutely devastated when a resident dies you know, it can take them a long time to get over it. We had a death [in a particular unit]… it's four years ago now … the staff there remember the date, we	• Absolutely devastated (staff) • It can take them a long time • The staff there remember	• Some of the staff can be absolutely devastated when a resident dies you know, it can take them a long time to get over it. We had a death [in a particular unit]… it's four years ago now … the staff there remember the date, we visit the grave. • I think it's the emotional attachment, you're there with the

to bereavement (personal and professional)	with service users. • In reflection of these challenges, there were personal and professional complexities associated with the challenges staff face, from their own feelings to the demands of their role.	visit the grave. • I think it’s the emotional attachment, you’re there with the person, somebody you cared for, and that they’re going out of this world. • ... it depends how close you are to the client and how you actually feel about [them]. • I think the point for us, working with clients or whatever, is that we have to be very careful where our stuff begins and ends for us as individuals, and be very careful of the spill over or effects we can have on the client too … it can happen very easily, people don’t mean it but people can be working out their own grieving piece at the expense sometimes of clients.	the date • Emotional attachment • How close • Careful where our stuff begins and ends • Spill over • Working on their own grieving piece at the expense sometimes of clients	person, somebody you cared for, and that they’re going out of this world. • ... it depends how close you are to the client and how you actually feel about [them]. • I think the point for us, working with clients or whatever, is that we have to be very careful where our stuff begins and ends for us as individuals, and be very careful of the spill over or effects we can have on the client too … it can happen very easily, people don’t mean it but people can be working out their own grieving piece at the expense sometimes of clients.

The role of the organization (topic 3) – subsection of theme: Perception by staff of a lack of awareness at organizational level re: impact of bereavement.	• The first theme - Perception by staff of a lack of awareness at organizational level re: impact of bereavement. • Some staff suggested that there was a lack of awareness about the personal and emotional impact on staff; that they were perceived negatively if they displayed a personal reaction.	• I guess my impression in the time I've been working here is that I would see that there's a huge lack of awareness and understanding across the whole of the organization really about the impact of loss and bereavement for people with ID… • A lot of the time you're like … considered to be emotional or something if you actually care or love a person with ID and I think that has to be addressed by the organization.	• Huge lack of awareness and understanding • Across the whole of the organization • Considered to be emotional or something • Care • Love	• Perceived negatively for modelling grief to clients! • Genuine relationship with PWID also disapproved of • Is there an organisational pressure to remain boundaried and strong that prevents staff from appropriately grieving. This surely has a knock on effect on clients who don't ever get to see people grieving – very different to when you don't live in care and see people grieve openly?
From discussion section of paper	• Emotional and interpersonal impact of sharing in the service user's experience of death – staff also have intense feelings of loss and isolation from the organisation at these times. • Acknowledged need for support in order to support PWID. • Lack of organisational support/awareness = difficulties providing bereavement support in house. • Lack of awareness of the emotive nature of care giving role.	n/a	n/a	• Extensive losses in ID services contrasted with a lack of organisational awareness and support. • Leaves staff trying their hardest to work things out as they go without appropriate support and training. • Ability to do this is impacted on by the emotional nature of the role and the strong relationships between PWID and carers – difficulties in offering support when so embedded within the situation.

Section Two: Research Paper

Staff's Relationship with Someone with an Intellectual Disability and Dementia: An Interpretative Phenomenological Analysis

Word Count: 7433

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Prepared for Research in Developmental Disabilities[1]

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[1] See Appendix 1-A for author guidelines

Abstract

There is a growing body of research relating to the support of people with intellectual disabilities who have dementia, however this has generally focused on the practical elements of this role. This study explored the experiences of ten paid staff who had supported people with an intellectual disability and dementia in supported living environments. An interpretative phenomenological analysis was used. Four themes were developed: (1) The value of the pre-existing relationship to staff as dementia progresses; (2) Finding ways to connect when reciprocity has gone; (3) Resisting dementia "creeping in" and taking control; and (4) The stronger the pre-existing relationship, the greater the emotional cost of dementia. The findings support previous research which suggests that people with intellectual disabilities and dementia are most appropriately supported within intellectual disability services. Participants' in-depth relationships enabled them to advocate for those they supported as dementia progressed, however this bond also had emotional costs. A number of recommendations for clinical practice have been offered in light of these findings, and direction for future research has been offered.

Keywords: Intellectual disability; dementia; paid staff; interpretative phenomenological analysis.

1. Introduction

Dementia is a condition which detrimentally affects a person's cognitive functioning (Ash, 2014; Prince et al., 2013), and usually comprises memory, communication and behavioural changes (Biernacki, 2007), ultimately leading to a deterioration in skills of independent daily functioning (Ash, 2014). There are many different types of dementia, the most common of which is Alzheimer's disease (Alzheimer's Society, 2007; Snowden, 2010).

Estimates suggest that by 2021 there will be over one million people living with dementia in the UK as the population ages (Alzheimer's Society, 2012). As healthcare, medical intervention, education and living conditions have improved (Prasher, 2005), the average life expectancy of people with intellectual disabilities (PWID) has increased from only 18.5 years in the 1930s, to 66 years in 1993 (Braddock, 1999). This places PWID at greater risk of developing dementia within their lifetime (Llewellyn, 2011; Prasher, 2005, Strydom et al., 2010). Furthermore, people with Down syndrome are known to be at greater risk of developing dementia, particularly Alzheimer's type (Beacher et al., 2010). The manifestation of dementia in PWID is often affected by their pre-morbid intellectual and cognitive functioning as well as environmental factors (Strydom et al., 2010).

In her review of the literature, Llewellyn (2011) concluded that diagnosis of dementia in this population is often confounded by other difficulties, such as an individual's ability to communicate, additional sensory difficulties or comorbid health difficulties with similar symptomology. Symptoms may be difficult to recognise (Whitwham & McBrien, 2010) and may be wrongly attributed to the person's intellectual disability (Whitehouse, Chamberlain & Tunna, 2000). Furthermore, multiple diagnostic tools are used to aid the diagnosis of dementia in PWID, with no clear consensus regarding the most reliable and useful approach (Llewellyn, 2011; Zeilinger, Stiehl & Weber, 2013). The British Psychological Society (2015) have recently updated guidance on assessment, diagnosis, intervention and support for

PWID and dementia. This document provides a useful overview of the available assessments and considerations regarding co-morbidity or alternative explanations for observable symptoms.

Given the apparent difficulties in diagnosing dementia in this population, paid staff can play an important role in identifying changes which may be related to dementia (Llewellyn, 2011). Many PWID live in supported accommodation whereby they receive support from paid staff (hereafter referred to as staff), often for much of their adult life (Gone, Hatton & Caine, 2012; Public Health England, 2014). Staff may therefore have in-depth knowledge of those they support, thus enabling them to notice subtle changes in behaviour and cognitive functioning over time which may enhance the information collected via the use of formal assessments (Hoekman & Maaskant, 2002).

Despite this in-depth knowledge staff often hold of people they support, residential services may be ill-equipped to support the progressive deterioration of those diagnosed with dementia, due to lack of appropriate knowledge and training relating to the condition (Fahey-McCarthy, McCarron, Connaire & McCallion, 2009). Nevertheless, it has generally been agreed that PWID and dementia may be best placed within ID services where this is possible, rather than moving into services that specialise in supporting people with dementia (e.g. Dodd, 2003; McCarron & Lawlor, 2003; Thompson & Wright, 2001). The concept of “ageing in place” (Janicki, McCallion & Dalton, 2000)), more recently referred to as “dying in place” (British Psychological Society [BPS], 2015 advocates the adaptation of ID settings to accommodate a person’s changing needs following the onset of dementia (Watchman, 2003). Furthermore, all public sector services in England have a legal duty to make reasonable adjustments for PWID to ensure the support they receive is appropriate to their needs (Turner & Robinson, 2011).

Dying in place has important implications for staff in residential ID settings, as they may have to support people who have developed dementia despite not necessarily having previous training or experience of this (Wilkinson, Kerr & Cunningham, 2005). Staff have highlighted the value of knowing the individuals they support very well, in that this enables them to learn the strategies that work best for the individuals they support (Fahey-McCarthy et al., 2009). However they have also reported a need for dementia-related training to increase their confidence in supporting PWID when they are diagnosed with dementia (Fahey-McCarthy et al., 2009). Dodd (2014) suggests the different training and support needs of staff in the different stages of dementia, from pre-dementia to end-of-life, highlighting the need for staff to adapt their approach in a person-centred manner.

In their study with staff who supported PWID and dementia in residential care home settings, Wilkinson et al. (2005) found that this role carries an emotional burden, yet concurrently they found staff to be very committed to ensuring PWID clients aged in place. Some participants reported going “above and beyond” their expected role in an attempt to minimise the possibility of the PWID and dementia being moved out of their current home, but noted that this was something that was rarely acknowledged by the service at the time. Similar findings were reported by Furniss, Loverseed, Dodd and Lippold (2011) in their service evaluation which explored the support needs of staff supporting people with Down syndrome and dementia.

Indeed, PWID and dementia have been reported in the literature to require increased time from staff than those without this diagnosis (Janicki, Dalton, McCallion, Baxley & Zendell, 2005; McCarron, Gill, McCallion & Begley, 2005), which can have a detrimental impact on staff wellbeing (Lloyd, Kalsy & Gatherer, 2008). For example, Lloyd et al. (2008) found that staff supporting adults with Down syndrome and dementia reported greater emotional exhaustion than those supporting adults with Down syndrome without dementia.

Wilkinson et al. (2005) also warned of the potential for staff to “burn out” if the demands of supporting PWID and dementia are not adequately met by services. Indeed, the recent Keogh Report (Keogh, 2013), which reviewed the care provided in hospitals in England, highlighted the importance of an engaged staff team in ensuring quality care for those that use services.

Existing literature regarding staff working with PWID and dementia focuses on the practical elements of this role, such as the extra shifts and longer hours that staff have reported (see Courtenay, Jokinen & Strydom, 2010, for a review of the literature). However, there is a lack of literature specifically exploring the staffs’ *relationships* with PWID and dementia.

Literature concerning people without ID highlights the relevance of attachment theory (Bowlby, 1969/1982) in the care of older adults (see Browne & Shlosberg, 2006, for a review). It has been posited that a diminished sense of security and safety experienced by adults with dementia can trigger an increase in “attachment behaviours” (Bowlby, 1979, p.129), such as attempts to seek closeness to another individual (Bowlby, 1979) as a means of alleviating the potential threat this may create (Miesen, 1992). Furthermore, literature from the ID field suggests that the attachment relationship between staff and the PWID is a crucial component of high quality support (Reinders, 2010; Schuengel, Kef, Damen & Worm, 2010). Schuengel et al. (2010) suggested that “extraordinary sensitivity” (p.39) is essential for staff if they are to promote a secure attachment relationship with the PWID that they support.

However, Reinders (2010) argued that recent endeavours within health services to demonstrate quality of care via easily measurable outcomes can impede such efforts to relate to those supported in services in a helpful way. The well-publicised failures of person-centred care such as those at Winterbourne View (Department of Health, 2012) and the Mid Staffordshire NHS Foundation Trust (Francis, 2013), while demonstrating the importance of care, compassion and sensitivity towards people using services, have potentially reinforced such efforts to “prove” quality through objectively measurable outcomes, which may be counterproductive.

1.1. Research aim

Despite the growing body of research in the field of ID and dementia, there has been little focus specifically on the relational dyads between staff and PWID and dementia. Consequently, in this research I aim to offer an insight into the lived experiences of staff in residential or supported living environments in terms of their relationship with PWID and dementia. Using qualitative methods, specifically interpretative phenomenological analysis (IPA; Smith, Flowers and Larkin, 2009), the in-depth lived experiences of this relationship can be examined in detail, ensuring sensitivity to the idiosyncratic nature of such relational dyads. Such insight will highlight exemplars of the impact a person’s dementia has on the staff involved in this research and identify some key features of relationships between staff and PWID that could be explored in more depth through further research.

2. Methods

2.1. Design

The chosen method, IPA, has an interpretative phenomenological epistemology (Larkin & Thompson, 2012), which is consistent with the research aim. This method is concerned with understanding the personal meaning for a participant of a particular phenomenon in a particular context (Larkin & Thompson, 2012). In-depth interviews enabled the researcher to explore how participants made sense of their relationship with a person with an ID and dementia. Participants’ sense-making was subjected to my own interpretation throughout the analysis, creating the “double hermeneutic” (Smith & Osborn, 2003).

2.2. Participants

Participants were paid staff in residential or supported living houses for adults with ID who had at least six months’ experience of supporting someone with an ID and dementia within the last five years. It was not essential that participants still worked with the person with dementia, for example, if that person had died, moved to a different residence, or if their relationship with this person was in a previous place of work. The majority of participants worked in different residences or organisations, however three participants were from the same residence and spoke about the same PWID. Ten participants took part in the research. Participant information and demographics are presented in Table 1.

<INSERT TABLE 1 HERE>

2.3. Procedures

2.3.1. Ethical approval

This study was reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

2.3.2. Recruitment

Participants were recruited from organisations in two areas of the North-West of England who provided supported living accommodation to adults with ID. Managers of known organisations within these two areas were contacted and asked to distribute recruitment materials (see Section 4: Ethics Section, p.4-21 – 4-35) to the staff within the individual residences in their organisation. In addition, I visited some teams on the request of managers to discuss the research further. Participants opted into the research by telephone or by returning an expression of interest form (see Section 4: Ethics Section, p.4-27 – 4-28). Interviews were arranged with those who met the eligibility criteria detailed in section 2.2.

2.3.3. Interviews

Interviews took place at participants’ places of work, their organisation’s office base or in an office at the local community ID service. Before beginning the interview, the participant information sheet (see Section 4: Ethics Section, p.4-23 – 4-26) was reviewed and participants completed a written consent form and an additional information/demographic questionnaire (see Section 4: Ethics Section, p.4-31 – 4-33). Participants assigned themselves and the PWID they wishes to talk about pseudonyms to maintain anonymity. Interviews, which were audio recorded, took place between September 2014 and January 2015 and lasted between 51 and 87 minutes (mean=69 minutes).

A topic guide (see Section 4: Ethics Section, p.4-34 – 4-35), comprising a series of open-ended questions designed to elicit information related to the research question, was used flexibly during interviews. This was reviewed and informed by representatives from an advocacy group for PWID, who shared ideas about what was important to them about their relationships with staff. The topic guide was refined as interviews progressed and I became more experienced at eliciting in-depth information that addressed the research question.

2.4. Analysis

Audio recordings of interviews were transcribed verbatim; all names were replaced with the assigned pseudonyms and other identifiers were removed. Each transcript was analysed in turn using the six step process outlined by Smith et al. (2009), which involved: (1) becoming immersed in the data by repeatedly reading the transcript; (2) making initial descriptive and interpretative notations related to the participant’s relationship with their client; (3) searching for emergent themes from the initial notations; (4) developing super-ordinate themes for the participant, by searching for connections across emergent themes; (5) moving onto the next participant transcript and repeating steps 1-4; (6) developing overall themes for the group of participants from their individual superordinate themes. An excerpt from one participant’s analysed transcript is provided in Appendix 2-A. Appendix 2-B illustrates the contribution of emergent themes and superordinate themes for this participant to the overall themes.

2.5. Quality of research

To ensure the research was of good quality, I was guided by four principles proposed by Yardley (2000): sensitivity to context; commitment and rigour; transparency and coherence; and, impact and importance. The eligibility criteria were used to ensure that the sample shared the experience outlined in the research aims, and I drew on my clinical and research experience while designing and conducting the research to ensure that data was of good quality. The research process was enhanced by research supervision, attendance of an IPA peer support group and membership of an IPA discussion forum. I aimed to ensure that the research was relevant to a number of personnel within the ID field throughout the design and implementation and sought to remain reflexive.

2.5.1. Reflexivity

Reflexivity refers to a researcher's awareness of how their characteristics and assumptions may influence the research (Finlay, 2002; Robson, 2002). I am a white female with a particular clinical interest in, and experience of working in, the ID field. I acknowledge that this is likely to have had an impact on the process of data collection, analysis and the conclusions drawn. To remain reflexive throughout the process, I have documented my reflections and discussed these within research supervision.

3. Results

Four themes were developed from the analysis of the ten participant interviews: (1) The value of the pre-existing relationship to staff as dementia progresses; (2) Finding ways to connect when reciprocity has gone; (3) Resisting dementia "creeping in" and taking control; and (4) The stronger the pre-existing relationship, the greater the emotional cost of dementia. These will be discussed in turn with supportive participant quotes[2] [3].

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[2] The omission of words within quotes is indicated by three ellipsis points (…).

[3] One participant quote contains the term "learning disability", which is often used interchangeably with "intellectual disability" in the UK.

3.1. The value of the pre-existing relationship to staff as dementia progresses

This theme illustrates the importance participants placed on having known the PWID prior to the onset of the dementia, or early in the progression of dementia, in helping them as the PWID’s condition deteriorated.

This pre-existing relationship gave them in-depth knowledge of the PWID’s likes and dislikes, which enabled participants to advocate for them as their condition deteriorated. Linda described the detrimental impact that not having this prior knowledge could have:

> You read through diary sheets and you see Phillip was up such a time during the night … So you’d look at … what’s he done … she’s given him coffee. Phillip *never* [emphasis added] drinks coffee … but the staff aren’t really aware of that because they don’t remember him from when he could talk and tell you what he wanted.

However, it appeared that this pre-existing relationship had value beyond simply knowing their preferences. Participants viewed their pre-existing relationships as giving them a privileged knowledge of the PWID, which they implied could not be achieved without having known them before the dementia progressed: “If somebody else come in, they might have been taught a different way of helping him stand, just something as little as that could ruin his day” (Andrea). This higher-order knowledge of the idiosyncratic elements of the PWID’s personality and character enabled them to consider the smaller details that they knew to have been important to them previously.

Furthermore, this privileged relationship enabled participants to “read” the PWID in a way that they felt could not be achieved without having known them before, as illustrated by Rose, who explained how she knew when Dan was having a bad day and was likely to become aggressive: “Nobody could actually put it in writing, but you could read his face”. This pre-existing relationship was not simply a professional relationship; some participants described the PWID as being like a member of family with whom they had developed an emotional bond, particularly because of the amount of time spent at work with them. This bond gave them a sense of loyalty towards the PWID which motivated them to help and advocate for them as their condition deteriorated: “You look out for them don’t you … as like you would your own” (Linda). Despite the perceived importance of this bond, participants were aware of a contradictory narrative within their organisations that discouraged staff from having more personal attachments to the people they supported, although it was unclear where this narrative originated. This was illustrated by Sophie:

> They always say a professional relationship can never be anything more than that … but it doesn’t work, how can it?! You can’t tell me you’ve worked with someone for five years and not have a bond … you *have* [emphasis added] to.

The value participants placed on their pre-existing relationship meant that it was important to them that the PWID remained at “home” as their dementia progressed. Participants believed that a lack of familiar relationships and environment would result in a poorer quality of life for the PWID, as suggested by Andrea: “We knew that if he got put in to a nursing home, he wouldn’t get the same level of care as what he would get here. He wouldn’t be happy, and he would fret himself to death basically.”

In contrast with most participants, Paul, who did not begin working with Robert until the late stages of his dementia, did not believe that it was necessary to have known him before his decline. However, unlike his relationships with other PWID in the same residence who didn’t have dementia, Paul had to invest in getting to know Robert vicariously:

> Listening to stories that he tells … it was really helpful to be able to talk to other staff members who could either tell me extra details or explain what he was saying … that would then enable me to converse with Robert.

3.2. Finding ways to connect when reciprocity has gone

This theme describes how participants reported adapting in a more practical sense to their relationship changing as the PWID's dementia progressed and how they had to find alternative ways to connect with them in light of these changes.

For most participants, their relationship prior to, or in the early stages of, dementia was one of mutual enjoyment and reciprocity with a relatively independent PWID. The reciprocity of this relationship resulted from the close emotional bond described in theme one. However, over the course of dementia, participants had to redefine their relationships with the PWID as it became more limited, and eventually, one-way. This is illustrated by Margaret:

> …the dynamics changing quite a lot because now it is much more about offering a lot of physical support and not getting as much back in terms of like banter … I mean it's quite sad to not have the same kind of *fun* aspect to it.

This change in relationship initially limited participants' ability to connect to the PWID, who was no longer contributing to the relationship as they once had. Maggie described how music, which was something she and Dave enjoyed together before his dementia deteriorated, no longer initiated a shared interaction: "That's quite hard … you're singing away and he's just sat there … you don't know if there's a connection with the music or not." Consequently, participants had to learn new ways to connect with the PWID that took into account their deterioration.

For many participants, understanding the cognitive and behavioural manifestations of dementia was crucial to aiding this connection, as this often gave them a rationale for why the person did not relate to them in the same way they used to. It also helped them to understand the day-to-day fluctuations in the PWIDs' presentations. This knowledge was often acquired through attendance of dementia awareness training. Participants were more accepting of dementia when they could understand the good reasons for the PWID’s lack of reciprocity. The impact of dementia awareness training was described by Andrea:

> I’ve never worked with anybody with dementia, and I was so glad when we went on this course … I learnt such a lot about dementia … So that when I came back to Percival, I didn’t feel like I was lost, climbing a hill you know.

Connecting with the PWID when dementia progressed was often a process of trial and error, however, by trying to take the person’s perspective, participants could maximise this connection. For example, some participants described trying to connect with the person’s reality in the moment, by attempting to understand where they were regressing to, as exemplified by Linda: “There’s no set rule because one minute they might be in 1975, and next minute, 1975 doesn’t exist.” For others, this involved capitalising on the PWID’s positive mood in order to get potentially distressing personal care tasks done quickly. Some participants highlighted the importance of managers having an understanding of the additional time required to support PWID and dementia.

It was noted by some participants that they were already well accustomed to making adjustments by nature of their role in supporting PWID, and that this skill was easily transferable to the changes associated with dementia:

> But things like that aren’t new to us … Having somebody who can’t remember what they ate 20 minutes ago. That could be somebody with a learning disability anyway. It just happened that Dave had those abilities and then he lost them. So I think … it’s just essentially what we do already. (Maggie)

Unlike the other participants, Paul described having never had a reciprocal relationship with Robert. Despite this, he still had to find ways to connect to Robert which differed from how he connected with Robert’s peers (who did not have dementia):

> One of the things that I always had to bear in mind was that I could get to know him, but he would never ever get to know me … With the other people they obviously had to get to know me as well as me getting to know them.

Despite the challenges participants encountered in attempting to connect with the person they supported as dementia progressed and the reciprocity diminished, it was evident that they still reaped rewards from their interactions.

> Seeing that breakthrough when he gets it makes it worth it for me ... if you can sit with him and eventually you know that he’s had a good meal ... that’s a real achievement that I feel proud of. (Paul)

3.3. Resisting dementia “creeping in” and taking control

This theme illustrates how participants tried to resist dementia from taking away the PWID’s identity and leaving behind a vacancy, which made it much more difficult to have a meaningful relationship.

Participants viewed dementia as something which gradually, and often silently, “took hold” (Andrea) over the PWID, involving a loss of abilities, self-esteem, dignity, and most importantly, their personality. As such, many participants described dementia as something that caused the person to “go downhill” (Linda) or “waste away” (Andrea). They viewed the PWID as “unfortunate” (Margaret) for having to endure this deterioration, as illustrated by Sarah: “It’s horrible, I think that is one of the worst illnesses that- I wouldn’t wish it on my worst enemy.”

Despite this acknowledgement of the person’s decline, participants tried to resist letting go of their identity and personality in the face of dementia, in an effort to maintain a meaningful relationship with the person that they knew: “[You] still treat him as a man and not as a ‘thing to be dressed’” (Matthew). Many participants described trying to maintain things that were unique to the person’s personality, such as what they would have chosen to wear when they were able to express their choice. Linda did this in a hope that it might remind Phillip of how he used to be:

> We know that he likes to be clean shaven, he likes to have a bit of cream on, he likes to wear a belt … cause these are things that might just trigger them memories off, you know? He is still the same person, it's just a different setup.

For some participants, maintaining the PWID's former identity seemed to be an attempt to protect them from becoming vulnerable. The vulnerability which accompanied dementia appeared to be in conflict with participants' efforts to promote the PWID's empowerment before the onset of the condition. This seemed to reflect a value held within participants' respective organisations, and more generally in ID services, of promoting the rights of PWID. Sarah remarked upon the impact this increasing vulnerability posed to Daphne, who used to feed herself: "So she was quite, I used to think as well, gosh she's so vulnerable, because you could just say you've had it when she hasn't had it really."

As the dementia "crept in" (Sarah), however, participants described becoming less successful at holding onto the identities of those they supported: "It was her, but it wasn't her" (Sarah). Participants described a shift from the PWID as an individual with a personality, to being physically present but vacant inside: "To go to just being sat hunched over in a wheelchair, with the occasional light coming on … the lid was shut basically … there was nothing getting in, nothing coming out." (Andrea). Some participants described the person with dementia as being like "empty shells" (Linda, Sarah). For some participants, this led to them taking on a more maternal role, as they began to care for them as though they were a baby or small child.

Surprisingly, some participants were more accepting of dementia's increasing presence. Some described a "mellowing" of the person as they reached the end of their lives. For Rose, Dan's increasing frailty was met with a sense of relief, as this prevented him from being able to physically attack her, as he did in the earlier stages of dementia. Paul acknowledged that dementia helped minimise Robert's potential distress by limiting his awareness of his physical and cognitive deterioration:

> His dementia was quite a blessing, in some ways, because his physical condition deteriorated quite a lot in the last couple of years … But because in his mind he is still walking round town, catching the bus, going to work, greeting people at the Post Office, whatever, he doesn't see his current condition. So that was quite a blessing I suppose.

3.4. The stronger the pre-existing relationship, the greater the emotional cost of dementia

This theme describes the emotional impact on participants of supporting someone with an ID through dementia, which was often greater if they had known them before, or in the earlier stages of, their dementia. It also illustrates some of the strategies participants used to manage these emotions.

Many participants experienced strong emotions and grief as they witnessed the PWID's decline during the progression of dementia. Linda described mourning the loss of Phillip's character, and her sadness that dementia seemed to have caused him unhappiness:

> I want him to go back to how he were, him being proper naughty and make me laugh and play card tricks and pinch me magazine … Cause he were well. And he were happy. And he doesn't seem happy to me anymore.

Of particular significance to many participants was the emotional impact of the person no longer recognising them as dementia progressed. This was illustrated by Andrea, who felt angry with, and rejected by, Percival: "It angered me the fact that he didn't know who I was after all these years." Many participants perceived this as somewhat invalidating of the relationship they felt they and the PWID had invested a lot in. As dementia progressed, participants felt rewarded by any sign of recognition from the PWID which acknowledged this relationship. Where this had not happened yet for some participants, a lack of recognition was reported to be the biggest fear, as illustrated by Sophie: “I don’t want him to forget me … Oh it’d hurt me that. It’s like three years of your life with him … So if that happened to me with Arnie, I’d be heartbroken.”

Some participants struggled to deal with the emotional cost of the PWID’s aggression towards them in dementia, which often challenged their capacity to remain compassionate towards them. Rose, who sometimes feared going to work in case she was attacked, illustrates the impact of this: “Not every day was horrible, but when you did have a bad day, you remembered it for a few days … [it] scarred you in some ways. Mentally and physically.”

Contrary to those participants who had a pre-existing relationship with the PWID, Paul described being able to focus on supporting Robert in the moment, without grieving the loss of identity others were adjusting to: “I think some of the other staff, either because they’d known him before, or because they weren’t used to working with dementia, expected him to be able to listen to them or remember how he should be.”

Participants employed a range of strategies for managing their emotions. Some participants tried to hide their emotions, as described by Andrea: “You just put up a front. You put everything into the back of your head, dig it down into your stomach, the pit of your stomach and you just get on with it.” However, this was unsustainable and several participants reported talking to managers, friends or family members as a way of discharging these emotions. Support from other members of the staff team was cited by several participants as being central to managing the challenges of dementia. This enabled them to take it in turn to support the person with dementia in order to have time out to recuperate. Several participants appeared to find comfort in knowing they had contributed to giving the person a “good life” and reassured themselves that they had “done enough”.

Some participants acknowledged feeling sad that the person had dementia, but believed that the expression of emotion would be detrimental to their care and wellbeing. Maggie described the importance of "not getting bogged down" in emotions. This pragmatism, however, appeared to be protecting Maggie from the sadness of watching Dave's deterioration. This was illustrated by her surprise at becoming very tearful within the interview and her apparent shame in doing so, suggesting that she viewed this as a weakness:

> I didn't think I'd do that. I thought it would be very … It's ok, I'll be alright in a minute, I'll be laughing in a minute, in a few minutes ((laughs)). I didn't think I'd get upset. That was silly.

Half of the participants interviewed had experienced the death of the person with dementia, which was understandably a very sad experience that left these participants with a feeling of loss. Some participants described a continued presence despite the person's physical absence, which seemed to help them grieve by maintaining a sense of connection. This connection was also maintained by post-death rituals and remembrances, which appeared to aid the grieving process experienced by all. This was the case for Katee, who gained some closure by seeing Frank in the chapel of rest, as he was before the dementia deteriorated:

> Seeing him on that last day, he was looking very smart, and it's the first look of Frank when I first met him, you know with his scarf with his tie … his cardigan, and Marks and Spencer clothes. And I said, yeh, this is Frank.

4. Discussion

This research explored how staff experienced their relationship with someone with an ID and dementia. The findings and implications will be discussed in relation to relevant literature. Limitations of the study and suggestions for further research will be offered.

The findings indicated that, for the participants in this study, supporting people with dementia to “age in place” (Janicki et al., 2000) or “die in place” (BPS, 2015) was achievable. It has been argued within the literature that residential ID settings may be more appropriate for supporting PWID and dementia than specialist dementia services (Dodd, 2003; McCarron & Lawlor, 2003; Thompson & Wright, 2001), and participants in this study were committed to ensuring that this happened. Indeed, participants highlighted that they were already sensitive to making adjustments to their practice for PWID within ID services, and therefore they were able make further adjustments with ease when the person’s dementia deteriorated and their support needs increased. However, the findings expanded upon the current literature by highlighting other important factors which endorse dying in place.

Participants often had a pre-existing relationship with the PWID before dementia deteriorated, which equipped them with in-depth knowledge of their likes and dislikes, enabling them to advocate for them as their condition deteriorated. Fahey-McCarthy et al. (2009) highlighted this knowledge held by staff when those they supported developed dementia. Participants in this study, however, indicated that providing quality support went beyond knowing the strategies that worked best for the person. Reinders (2010) and Schuengel et al. (2010) argued that the attachment relationship between staff and PWID is important in ensuring care is of high quality, and participants in this study described having well-established emotional bonds with the person with dementia, who they often described as being like their family. This motivated participants to want the best for them and helped them to provide support unconditionally despite the challenges faced in dementia.

This bond also gave them a privileged knowledge of the person which they felt could not be achieved without this relationship. This is consistent with Reinders’ (2010) notion of “tacit knowledge” (p31), which describes the higher order knowledge of a supported person which can only be accessed via a personal relationship. Such knowledge, he suggested, enables staff to gain idiosyncratic insight into the person’s needs. While Reinders’ argument does not relate to people with dementia specifically, it could be argued to be even more crucial as dementia develops, due to their difficulties expressing their own needs as they may have done previously.

While this supports the value of PWID and dementia being supported for by those who know them well, Paul demonstrated that this pre-existing relationship was not essential. However, his ability to develop a relationship with Robert was reliant upon his investment in, and “extraordinary sensitivity” (Schuengel et al., 2010, p.39) towards Robert, which Schuengel et al. (2010) argued was vital if PWID are to form a secure bond with staff. Paul highlighted the importance of other staff who held this privileged knowledge in his ability to do this successfully. This suggests that, in order for quality support to be provided to PWID and dementia, having some staff who know the person well, and knew them prior to their deterioration, is essential.

Although the findings suggest that participants from this study were well-placed to support people with dementia to die in place, it also highlighted a number of challenges which made this role more difficult for them. Many participants expressed their lack of knowledge and understanding about dementia, which was also identified by Wilkinson et al. (2005). This was often rectified by participants’ attendance of dementia awareness training. Fahey-McCarthy et al. (2009) found staff from ID services who lacked knowledge of, and therefore confidence in, supporting PWID with dementia felt more prepared for providing quality dementia care following training related to dementia in PWID. Participants in the present study reported difficulties reconciling the changes in the person they supported, particularly when they interpreted such changes as invalidating their pre-existing relationship. Dementia training enabled participants to understand the impact of the condition on the person’s personality and behaviour, thus providing them with a rationale for why the person no longer related to them as they had before the deterioration of dementia. Consequently, participants could better manage the personal emotional impact of the changes to their relationship. These findings highlight the crucial role of dementia awareness training in the successful implementation of dying in place.

Another factor which challenged participants to support dying in place was the tension between the importance they placed on the relationship in providing quality support to PWID, and a narrative within their organisations that personal bonds were discouraged (although the origin of this message was unclear). As discussed above, participants' emotional bonds appeared to be a strong motivator in the support they offered to the person with dementia and it was apparent that participants' awareness of this narrative did not deter them from pursuing a more personal than purely occupational attachment. While participants believed these personal bonds to be crucial in providing quality support, they also increased the emotional cost to participants. Wilkinson et al. (2005) found there to be an emotional burden of supporting PWID and dementia, however this was largely attributed to the increased stress levels that working extra shifts and other practical issues created. Participants in this study experienced the emotional impact of losing the personality they had got to know, describing the PWID as being vacant inside. This loss in life could be understood as ambiguous loss, which Boss (2010) used to explain the unresolved grief experienced by staff when the person they support is physically present but their psychological presence is deteriorating, as with dementia. Participants initially tried to resist letting go of the person's personality and character, but also described the dementia "creeping in" gradually which appeared to be a parallel process to their grieving. This is consistent with Doka's (2010) description of grief as the "constant, yet hidden, companion" (p.15) of dementia.

Half of the participants in this study had experienced the death of the person with dementia, which led to further grief. However, death did not signify the end of their relationship. In contrast to the physical presence and psychological absence when the person was alive, there was a switch for some participants to a physical absence but a continued presence. Death allowed these participants to reconnect with the happier memories of the person, specifically their uniqueness and personality, and they used remembrances as a way of holding onto their relationship. This is consistent with the continuing bonds understanding of grief (see Klass, Silverman, & Nickman, 1996), which suggests that a continued relationship with the deceased can aid the grieving process and that death should not sever that relationship.

4.1. Clinical implications

The findings of this study highlight the importance of staff having the appropriate knowledge to enable a person-centred approach to working with someone with dementia. Dodd (2014) discusses current literature regarding the implementation of dementia training to staff teams and highlights the importance of adopting a systemic approach to embedding new learning into the service culture, thus promoting more sustainable outcomes. She suggests a staged approach to training and support, whereby staff are encouraged to adapt their approach as the needs of the person they support change, ideally based on a model of dementia. Buijssen’s (2005) two laws of dementia – the law of encoding and the law of roll-back memory – would provide staff with a framework within which to understand the person with dementia and thus respond in an appropriate manner.

Clinical psychologists are well-placed to offer such training (Jones & Hartley, 2015), within which they could support staff to develop individualised formulations (BPS, 2015) to contextualise the person’s current presentation. It is anticipated that timely training and formulation would increase the knowledge, skills and confidence of staff in continuing to provide excellent support to the PWID, despite the challenges illustrated in the findings of this study as participants encountered the changing needs of those they supported.

One-off training, however, is likely to be insufficient. In order to sustain staff's confidence in supporting individuals with dementia, this should be complemented by psychological consultation (BPS, 2015) at times when staff face difficulties in their support role. The recent BPS dementia guidance offers several case studies demonstrating how consultation can improve staff confidence and highlight when further training or reformulation is required in light of the individual's dementia progression.

Consultation sessions may also be a forum within which staff could be supported to manage their own emotions (Dodd, 2014), as highlighted by the findings of this study. If staff feel emotionally contained, then this would reduce the potential for them to burn out, which Wilkinson et al. (2005) highlighted as a real possibility. Seager (2014) argues that in order to sustain a caring role and reduce potential burnout, staff need ongoing support within an empathic and compassionate organisational culture.

While the goal of these interventions is to promote the knowledge, skills, confidence and psychological wellbeing of staff supporting PWID and dementia, the ultimate goal is to ensure that the PWID themselves achieve the best quality of life possible.

4.2. Limitations

This study aimed to explore the in-depth lived experiences of ten participants'' relationships with a person with an ID and dementia and therefore the use of what could be considered to be a relatively small sample was a conscious decision in the planning of the study. Indeed, it has been argued that IPA can lose its idiographic purpose when larger samples are employed (Hefferon & Gil-Rodriguez, 2011; Smith et al., 2009).

However, it should be noted that three participants worked within the same residence with the same person with dementia, and some participants shared an employing organisation but worked in different residences. IPA focuses on a person's lived experience and therefore each experience will be unique. However, it is possible that participants from within the same residence or organisation may share similar organisational values and ideas. Nonetheless, themes were drawn from all ten participants' experiences and therefore represented the range of participants within the sample.

4.3. Future research

The findings of this research could contribute to the development of an empirically-based theoretical model highlighting factors that are important for staff supporting PWID and dementia in community ID services. Future research could test this in order to determine whether the examples of participants'' lived experiences identified in this study represent a wider pattern of experience, that is, whether they can be more widely generalised.

For example, this research raised some important issues regarding the emotional support needs of staff working in a support role, and the understanding of these needs on an organisational level. These issues would benefit from further in-depth qualitative exploration, for example, specifically exploring staffs' experiences of ambiguous loss when supporting PWID and dementia.

It would also be worthwhile to evaluate the impact of the recommendations for clinical practice outlined in section 4.2. Such evaluation could measure staffs' psychological wellbeing and confidence in managing the challenges of supporting PWID and dementia before and after training and psychological consultation using quantitative measures. The impact of such intervention on day-to-day practice could also be explored qualitatively and the mechanisms by which this knowledge is applied in practice could be considered.

4.4. Conclusions

This study supports previous research which suggests that residential services for PWID are well-placed to support PWID and dementia to die in place. It has highlighted the value of the tacit knowledge held by staff of those they support, which aided this support as the person deteriorated and became more dependent. The findings also raised a number of challenges to dying in place, which could be reduced by the provision of support for staff, both in terms of developing knowledge and skills in dementia care, and in managing the emotional impacts of this role.

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Table 1

Participant demographics and additional information

Participant[4]	**Age (years)**	**Length of time working as paid staff for PWID (years, rounded to nearest 0.5 year)**	**Number of people supported with ID and dementia**	**Length of time supporting the PWID and dementia (years)**	**Currently supporting the person with dementia? (Yes/No)**	**Completed dementia training? (Yes/No)**
Matthew	58	9.0	1	1.4	Yes	Yes
Margaret	52	15.0	1	10.0	Yes	Yes
Maggie	55	31.0	1	9.75	Yes	Yes
Paul*	29	2.0	1	1.25	No – deceased	Yes
Katee*	35	9.0	1	7.0	No – deceased	Yes
Linda	47	14.0	3	8.0	Yes	Yes
Andrea*	55	23.0	1	23.0	No – deceased	Yes
Rose	58	6.5	2	3.5	No – deceased	Yes
Sophie	24	3.0	1	3.0	Yes	Yes
Sarah	39	5.5	1	3.5	No - deceased	Yes
Mean	**45.2**	**11.8**	**1.3**	**7.04**	**-**	**-**

*Participants marked with asterisk all worked in the same residence with the same person with dementia.

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[4] All participant names are pseudonyms

Appendix 2-A

Excerpt from Andrea's analysed transcript

STEP 2: INITIAL NOTING	LINE NO.	TEXT	STEP 3: EMERGENT THEMES
Describes what it was like feeling lost – seeing him change from independent to not being able to talk properly. Didn't know what to do.	639	**I: Is that what it felt like to start with, that you felt lost and-**	Don't take it as personally when you understand the reasons for lack of recognition.
	640	A: Yeh, cause you just, I didn't as a per- I didn't really know what to do.	
Go off in like a blank – how did this affect the relationship – how do you have a relationship with a blank other?	641	Because to see him go from so independent and so able, to getting himself	
The video on training helped her to understand the function of some of Percival's behaviours. Once she understood the function, it was easier to maintain the relationship and support him better. The relationship pre-dementia seemed to be based on a good understanding of each other – seems normal to feel helpless when you lose understanding.	642	frustrated cause he couldn't get his words out. He used to go off in like a	Dementia – hard to relate to a 'blank'
	643	blank- When he was walking still, he used to go wandering. Now we learnt	
	644	from this video, the wandering was because they couldn't find what they	Understanding the function of behaviours helped repair relationship difficulties – better support
	645	were thinking about, and they were looking to see what it was that they'd	
Understanding enabled better support.	646	lost in their own head. So I used to walk with him, and I used to like, "Do	
	647	you want to go to your bedroom to watch TV?", or "do you want to listen	
	648	to your music?" or "is it a cigarette?", and sometimes that triggered things	Helpless when lose good understanding that you have built up.
	649	like that, yeh, he wanted a cigarette. Or he'd want a cup of tea, so he'd sit	
	650	and have his biscuit with his cup of tea, it was just little things like that.	
	651	Which before the video, he used to be up wandering, and we used to	
	652	think, you know, "Come and sit down Percival", I used to say, cause I	Training helped with perspective taking.
	653	didn't realise in his head that's what he was wanting. And the other one	
	654	was- Sorry, I've lost my track of thought. … On the video as well, they	
	655	told us about, well they showed us about like the times of day and stuff.	
Gives example of his getting up/going to bed routine and how it changed with the dementia.	656	Well Percival would, he'd want to be the first up, and he'd want to be last	
	657	to bed basically. So that he could get a full input of his day. And he got	
	658	where, he always wanted to be up early, but he wasn't bothered whether	
	659	he was first or not. But the going to bed. You know, he could have his tea	
	660	and then he'd be wanting to go and put his pyjamas on. When he was	
	661	able, he would come back with his pyjamas on. We'd say "Percival, we're	
Andrea couldn't understand his behaviours. This must have been really hard – seeing him change like this.	662	going out love", you know, "I thought you wanted to go to the pub or	
	663	something?" And I couldn't understand why he was wanting to go to bed	
	664	so early, you know, it could be five or six o'clock and he's wanting to go to	Early dementia – couldn't understand behavioural changes – hard to relate.
	665	bed, you know? And-	

Lack of understanding of behavioural changes.
In their head, they resort back to like a child, where you've got, you have got to be like a parent that guides them, encourages them to drink, eat – this is the point where their relationship changed from being one of equality and reciprocity, to one of caring them in a parent-child way – more of a hierarchy. Did Andrea not understand because she valued their equality and this felt very different?

Acknowledges this change from friendship to motherhood. Not just a mother but *like a concerned mother* – still cares for Percival despite change in the nature of their relationship – although I wonder why she had become a mother rather than a carer? Is this a reflection of how much she cares for him and how she views their relationship as beyond a professional one? Describes mothering him to ensure his basic needs were met
As wrong as this sounds – before when she has been talking about the closeness of their relationship, she hasn't felt a need to comment on their closeness. Now she is referring to Percival being like her child she is acknowledging that I might think this sounds unusual. Or does she mean it sounds wrong because Percival was in his 70s and she was quite a lot younger?
Had to mash his food - like a baby
Reflects on this transition from friends to parent-child. This seems like a very significant change in their relationship – a loss of equality But understood this to be essential after watching the video. *In many places* - not everywhere – don't always need to mother him?
Reflects on how she used to anger him by challenging him when he didn't recognise her.
Admits that she was angry that he didn't recognise her after so many years.
Angered me – very strong emotion – really had a big impact. She said earlier she was upset – now she is admitting it was more than feeling sad, but angry because of the time they had both invested in the relationship. *After all these years*

Reflects on what she learnt on dementia training – talks about it being useful, but it seems this was more for her than Percival initially – so that *she* could reconcile her anger about him not recognising her.

Recognises that Mark did this too and caused Percival anger – then Percival was happier when he eventually went along with it.

I: What was that like for you? That sort of feeling of not knowing what's-

A: Well, like, I was saying to Graham, "I just don't understand what's going on". I said "He's never done this before", I said "Why suddenly is he wanting to go to bed so early?", you know, "he's not wanting any supper and I'm having to coax him to have a drink" and stuff like that. And I couldn't understand because obviously I didn't realise that in their head, they resort back to like a child, where you've got, you have got to be like a parent that guides them, encourages them to drink, eat-

I: Do you think- Did it affect your relationship with him at that point do you think? Not really knowing what was happening?

A: Erm, I think I became from a friend to going to more a mother. I became like a concerned mother. And I felt like he was like – as wrong as this sounds – I felt like he'd resorted to being my child, you know, and that I had to kind of mother him to make sure that he ate, that he went to the toilet, that he drank, that he could still have his cigarette. And that he was still able to have all his foods that he did enjoy. But he couldn't chew. He lost the ability to chew and swallow. So everything had to be mashed to a fine thing. Like sort of, er, I don't know, I felt like I'd gone from an equal par of friends, to a mother-child. And after watching the video, I understood that's what, in many places, was needed. And also like when he wasn't referring to me as Andrea, "You're not Andrea", again, I didn't understand that at first, and I'd say "I am Andrea, Percival, it's me! You know, what are you talking about, it's Andrea!" and that used to anger him. But it angered me the fact that he didn't know who I was after all these years. And I didn't like- I had no understanding of dementia to be honest, whatsoever. Until I did this course and just that one video, I learnt so much from that one video. It was so useful, it really was. So I understood that even though he didn't know who I was, he still had that recollection of my voice. Just for other people to- Because we did have, Mark in particular, he'd just started and he'd worked with people at another place, and he wouldn't be called Graham, he'd say, "No my

Early dementia – losing the person you know so well.

Relationship changed from one of equality and reciprocity, to caring for him as a parent would for their child.

Lack of understanding due to poor fit with equal relationship.

Relationship changed from friend to concerned mother.

Role changed as he became more dependent on her – maternal duties to meet basic needs.

Dementia made Percival child/baby-like.

Loss of equality as dynamic changed.
Easier to cope with changing relationship when had a better understanding of dementia.

Angry by lack of recognition initially – invalidated years of investment in relationship.

Anger eased when understood dementia.

Dementia training helped her to reconcile her anger – dealing with emotional impact.

Appendix 2-B

Contribution of Andrea's emergent and superordinate themes to the overall themes.

Overall Theme Number	Overall Theme Name	Andrea's Superordinate Themes that Contributed to Overall Theme	Andrea's Emergent Themes that Contributed to Superordinate Themes
1	The value of the pre-existing relationship to carers as dementia progresses	Reciprocal and equal relationship prior to dementia and early dementia – more than a professional relationship	Frequent personalised gifts as a demonstration of the strength of their relationship Development of trust over time important aspect of their relationship. Good relationships require two people to spend time together. Have to make time to make relationship work. Time spent together deepens the relationship. Relationship development is hard work. Relationship is an investment. Relationship as comprising less support pre-dementia. Early relationship characterised by trust in Andrea Important relationship – willing to deepen this and integrate into the family. Introductions to Andrea's family. Relationship exceeding that of a professional relationship – like family. Resembles a friendship (rather than a work relationship). A favourite lady job vacancy. The promotion to "number one lady" a sign of their connection. Starting low in the hierarchy of Percival's relationships. Andrea working hard for his trust. The one = his favourite – she is the one too, special to him. Special relationship with Percival Percival was awarded love – an indication of the depth of the relationship – like family. Personal relationship – comprised love. Harmonious relationship a good foundation for a closer future relationship. Going beyond the carer role. An unclear boundary between professional and personal. Frustration of management imposing boundaries. A lack of understanding of rationale for boundaries. Feeling punished for intensity of relationship. Punished for caring.
		Investment - Using privileged knowledge of the past to	Long-term relationship with Percival See him as family – make choices for his future needs. It was important for him to be smart.

become an advocate	Assumptions about his wishes and advocating for someone based on prior knowledge / relationship Relationship and knowledge of the individual made Andrea strive to act in his best interests. As dementia progressed, Andrea had to protect, advocate for and fight for his wishes. Relationship important in understanding a person’s individual needs. Prior knowledge important when dementia progresses – enables care to be person-centred. Not having a relationship had the potential to ruin his day. Privileged knowledge crucial to happiness. Committed to maximising his enjoyment in life, based on prior knowledge of what he liked. Knowing little details is important. Subtlety of inside knowledge –not available to ‘outsiders’ Relationship gives Andrea the power to maintain happiness. Using privileged knowledge to ensure rest of staff team are consistent. Length of her relationship helped others understand Percival’s regression. Pride in in-depth knowledge of his life reducing stress level. Importance of past knowledge. Andrea has privileged knowledge of what was best for Percival that others (hospital) wouldn’t have. Important in his happiness. Prior relationship/ history gave Andrea privileged access to his mind. Usefulness of helping others to adapt to his regression was also sad for Andrea to see. Committed to stay with Percival until he died, even though relationship no longer reciprocated. Maintaining his preferences for being smart even when he couldn’t do so actively. Committed to maintaining dignity Importance of maintaining what is important to Percival even if there are personal costs. Maternal/ familial. Pride in maintaining happiness until he died. Never giving up on supporting him. Andrea’s relationship with Percival was unconditional – *wanted* to make sure he was happy to the end- more than job. Loyalty to Percival despite dementia. Relationship like family unconditional care. Persevered with meeting his needs/ honouring his wishes until the end. Maintaining person-centred care was a challenge Andrea et al succeeded at. Always thinking about what he would want and weighing up costs/benefits of adapting care as dementia progressed. Adapting to his needs regardless of the demands of this. Willing to go to great lengths. Nursing homes wouldn’t have the same in-depth knowledge as me. Going to great lengths to care for him through dementia.

			Important to maintain his happiness through dementia. Protecting him from a ‘bad death’ in hospital Andrea values relationship in him having a good life.
2	Finding ways to connect when reciprocity has gone	Finding ways to cope with the dementia identity and make the relationship work. Changing dynamics of the relationship.	At a loss when didn’t understand dementia. Increased support Support needs increasing over time. Dementia created hidden aspects of the relationship that Andrea had to work out. Less open. Going with where Percival was at reduced distress. Pre-training – couldn’t take his perspective, which caused him distress. Anger eased when understood dementia. Dementia training helped her to reconcile her anger – dealing with emotional impact. Finding ways to get something out of relationship despite him not explicitly reciprocating. Getting on his level improved her relationship with him – reciprocal gains – both happy. Amount of time spent at work forces adjustment and resilience. Minimise emotional impact of dementia as you adjust to it. Putting up a front Adjusting practically to him not recognising her, but emotionally still difficult. Supporting Percival as dementia progressed a process of learn-by-error – like starting a new relationship. Problem solving in re-building relationship with “Percival plus dementia” Relationship required more effort when dementia progressed – had to work hard to get into his head. Understanding the function of behaviours helped repair relationship difficulties – better support Training helped with perspective taking. Understanding dementia freed her up to adapt to Percival’s needs, rather than being caught up in emotional impact on her. Dementia training helped develop understanding. Don’t take it as personally when you understand the reasons for lack of recognition. Music as a way to connect to his own world. Adjusting to reality of relationship no longer being equal – hardening. Process of adjustment from managing own distress, to putting his needs first and adjusting to what worked for him.
		Reciprocal and equal relationship prior to dementia and early dementia – more than a	Getting something out of their relationship. Related to Percival as being like someone without an LD (pre-dementia) Andrea valued altruism in their relationship. Importance of Percival’s ability/attributes in terms of forming a relationship

		professional relationship	Possibility of a meaningful relationship. Seeking opportunities to develop the relationship. Developing a relationship with Percival as a choice Andrea made. Allowing Percival to participate with staff conversations was important to Andrea. Equality. Andrea found it easy to get on with Percival. An awareness that relationships make Percival happy a motivator for her to develop a good relationship with him. Two-way relationship earlier on Percival trusted Andrea pre-dementia Used to confide in Andrea. Mutual importance of developed relationship – both got something out of it. Getting something out of the relationship with Percival.
		Invalidation – the emotional impact of loss of relationship	Dementia – hard to relate to a ‘blank’ Early dementia – couldn’t understand behavioural changes – hard to relate. Early in dementia Andrea felt ‘lost, climbing a hill’- early struggle, didn’t know where to go. Easier to cope with changing relationship when had a better understanding of dementia.
		Progression of dementia increasing maternal relationship	Use of “we” – towards the end of life, less of a one-to-one relationship, and more input from other staff as a whole team effort.
3	Resisting dementia “creeping in” and taking control	Losing identity as an individual in dementia	Dementia “creeping in” Disappearing independence/ability When he got a diagnosis, it all “took off” Changes subtle in early dementia. Pitying his situation. Increase in changes Dementia very life-limiting nothing getting in or out eventually – ‘the occasional light coming on’; ‘the lid was shut’ Loss of dignity with dementia. Dementia strips dignity away over time. Dementia – own silent little world. Percival “wasted” away. Inequality in relationship when dementia progressed – Percival trapped and she is free to go home. Percival changed from being someone capable, independent, proactive individual, to a passive individual with an on/off switch.

		Loss of identity as an individual – from happy chappy to a former being of himself. Dementia ‘taking hold’ of someone. Change from someone very able and independent to someone ‘zonked out’ like passive old man. Speaks about Percival with dementia in a more pitying way – sympathy for his situation.
	Progression of dementia increasing maternal relationship	Mum until the end. As dementia progressed, friendship lessened and maternal relationship increased. Relationship protective – Andrea aware of the past treatment in hospitals. Maternal relationship Loss of equality as dynamic changed. Dementia made Percival child/baby-like. Dementia – from a grown man back to a baby. Maternal relationship – staff like adolescent children coping with it without her. Relationship changed from friend to concerned mother. Role changed as he became more dependent on her – maternal duties to meet basic needs. Relationship changed from one of equality and reciprocity, to caring for him as a parent would for their child. Accepting role of mum Residence as a home – family.
	Invalidation – the emotional impact of loss of relationship	Lack of understanding due to poor fit with equal relationship.
	Finding ways to cope with the dementia identity and make the relationship work. Changing dynamics of the relationship.	Relationship still there inside Percival, but no longer accessible due to dementia. Occasional spark/connection to remind her of the old Percival. Over time, able to hold in mind good and bad aspects of her relationship with Percival – adjusting.
	Investment - Using privileged knowledge of the past to become an advocate	Importance of maintaining his ‘old personality’ despite progression of dementia – protective of the old self. Maintaining his preferences for being smart even when he couldn’t do so actively. Committed to supporting him to do as much as he was able Andrea doing her best to maintain his good reputation with those that knew him despite behavioural changes with dementia. Promoting independence until no longer beneficial to Percival.

			Importance of weighing up what he gets out of supporting him to do things he used to enjoy. Meeting his needs. Important of her maintaining as much independence as possible for as long as possible.
4	The stronger the pre-existing relationship, the greater the emotional cost of dementia.	Invalidation – the emotional impact of loss of relationship	Angry by lack of recognition initially – invalidated years of investment in relationship. Emotional impact when the relationship has no give and take. Not getting anything out of it. Emotional impact of giving lots but receiving nothing back. Huge emotional impact of showing no recognition /acknowledgement of their prior relationship. From love to rejection – heartbreaking. Mismatch between overt coping and feelings inside. Strategies to distance self from the emotional impact of dementia Releasing pressure of emotions ‘resets’ ability to deal with emotional aspects of changed relationship/dementia at work. Importance of having outlets for emotion to prevent ‘bottle from overflowing’ Dementia robbed Andrea of her privileged “top dog” knowledge of Percival Overwhelmed by losing understanding of the person she knew so well. Emotional impact of seeing a change from independent and alive to dependent, shrivelled old man. Change in the level of recognition as dementia progressed (greeting her with pictures → not knowing her at all) caused hurt and upset. Loss of understanding made Andrea feel disempowered. Helpless when lose good understanding that you have built up. Early dementia – losing the person you know so well. Dementia threatened their strong relationship – ‘loss’ of the person you know so well. Invalidates the knowledge you have built up. Importance of relationships being two-sided – Andrea the one experiencing pain, not Percival.
		The cost of having a strong relationship – grief in death	Relief that wasn’t present at his death - did not distort her happy memories of relationship. Emotional attachment would have hindered her ability to deal with death had she been there. Misses their relationship. Grief a result of the importance of relationship and the emotional attachment. Unresolved loss – interview the first time Andrea had talked about impact of loss of relationship. Emotional impact despite being a job Emotional impact of attachment. Missing him while still alive. Importance of relationship in caring role means that dementia has a heart breaking effect as

	it progresses. Emotional to reflect on their relationship. An assumption that it is not professional to get attached to clients, but an acknowledgement that this is impossible to avoid with certain clients. Acknowledging the pain of her loss – demonstrates depth of their relationship. Processed emotional response to death at home before returning to work.
Finding ways to cope with the dementia identity and make the relationship work. Changing dynamics of the relationship.	Minimise emotional impact of dementia as you adjust to it. Putting up a front Adjusting practically to him not recognising her, but emotionally still difficult. Emotional impact of lack of recognition compensated by occasional recognition, and voice recognition. Hiding/burying/getting rid of distress and emotion a survival strategy to maintain a supportive relationship. Don't take it as personally when you understand the reasons for lack of recognition. Discharging buried emotion outside of work through relaxation, crying, getting support from family. Talking to manager to deal with emotion. Lucky to have people who understand impact of dementia on her relationship. Andrea got support from staff to deal with emotional impact of changing relationship. Adjusting to reality of relationship no longer being equal – hardening. Explicit adjustment a front to hide an inner pain. Process of adjustment from managing own distress, to putting his needs first and adjusting to what worked for him
Continuing the relationship after death	Won't forget happy memories of relationship. Remembers him fondly as someone younger and more able. Remembers the early relationship more than the later relationship now he's gone. Home important - familiarity Post-death actions driven by Andrea's relationship with Percival. Photographs only relevant to those in his "family" – relationship Honouring importance of relationship through post-death rituals. Importance of burying ashes at "home" – a way to continue the relationship. Ongoing relationship – showing him that she still cares. Importance of acknowledging her relationship with Percival at funeral. Pride in good funeral. A demonstration of their relationship. Keeping hold of closeness after death as a way of dealing with grief. Continues to consider preferences after death. Using knowledge of Percival to continue to honour death.

		Importance of seeing body for closure and reassurance that he died peacefully / saying goodbye. Importance of knowing Percival when planning funeral. Disposing of memories threatening ongoing relationship after death. Keeping a record of their relationship at home as a way of honouring the importance of their relationship and dealing with grief. Importance of not forgetting him after death Duty to ensure that PWLD are remembered and their absence not seen as a ‘vacancy’ . Remembering validates the ‘realness’ of the relationships in LD residences. Relationship continued after death. Importance of his “home” Managing own grief through continuing relationship
	Investment - Using privileged knowledge of the past to become an advocate	Importance of maintaining what is important to Percival even if there are personal costs.

Section Three: Critical Appraisal

Reflections on the Process of Conducting Research on an Emotive Topic

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Prepared for Research in Developmental Disabilities[1]

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[1] See Appendix 1-A for author guidelines

1. Introduction

In this paper I will appraise the process of conducting research into staff's experiences of their relationship with someone with an intellectual disability (ID) and dementia. The research paper can be found in Section 2 of this thesis. It has been informed by the reflections I have documented throughout the research journey including the issues of personal salience. I will begin by discussing the inception of the research idea, the development of the research aim and the choice of methodology, followed by my reflections on the issues raised by the recruitment process. I will then discuss the impact of researching an emotive topic, both for participants and on a personal level, and conclude with some final reflections on the research process.

2. Development of the Research Idea

2.1. Inspiration for the research

My interest in conducting research in the field of ID arose following my clinical experience prior to doctoral training. This experience, as well as my ID placement experiences on training, highlighted to me the important role of paid staff in the lives of people with ID (PWID). Many PWID live in supported living environments (Gone, Hatton & Caine, 2012; Public Health England, 2014) and much of my clinical work in ID settings has involved supporting staff in such residences. When working therapeutically with PWID, I have always been encouraged to consider the wider system and the different factors which may contribute to a client's presenting difficulties. When working directly with PWID, the support of staff has been invaluable in helping PWID to generalise their learning into their day-to-day life. This was highlighted by Beail and Jahoda (2012) as an important consideration for clinical psychologists who are considering beginning direct therapeutic work with PWID. As discussed by McBrien and Candy (2012), clinical psychologists often work with staff teams rather than working directly with the client. My clinical work in ID settings has often involved helping staff to understand a person's behaviour better and consider how they can make a positive difference to them.

Furthermore, I have been very aware of the recent enquiries following the care failings at Winterbourne View (see Department of Health, 2012, for the report on this), which were exposed in a UK television documentary in 2011. Several staff were jailed after being found guilty of abuse (Nadeem, 2012), however responsibility has also fallen to managers for a lack of effective leadership and supervision of staff (Parish, 2012). Seager (2014) highlights the potential to assign all blame to individual staff members for such care failures, when there are often wider systemic contributing factors. These issues highlighted to me the importance of better understanding the experiences of staff who support often vulnerable PWID, so that such systemic failures can be avoided in the future. For these reasons, I decided that I wanted my research to explore the experiences of paid staff supporting PWID.

I then consulted various professionals working in community ID services to gain a better understanding of the salient issues encountered within their roles. One issue raised was the management of dementia in ID settings. I have been aware of dementia since I was young, having supported a family member who was diagnosed with Alzheimer's disease. As a result of this interest, I completed a service-related research study as part of my doctoral training exploring service-users' experiences of a memory assessment service. It therefore felt natural for my research to combine my clinical and research interests in some way.

2.2. Developing the research aim and choosing methodology

Having explored the research relating to ID and dementia, I found the majority of papers involving paid staff to focus on the more practical aspects of supporting PWID with dementia in care settings (see Courtenay, Jokinen & Strydom, 2010, for a review of the literature). However, I was intrigued by the lack of research concerning how dementia might impact on staff's relationship with the person, given that many staff members I have met in

ID settings have worked with those they support over a long period of time. I decided that it would be both interesting and of clinical utility to qualitatively explore staff's experiences of their relationship with a PWID and dementia.

I then considered the most appropriate method of eliciting staff's experiences and analysing the resulting data. As the research focused on relationships, interviews were deemed to be the most appropriate method of honouring the subjective nature of relationships. I spent some time researching the different qualitative approaches which I could have used to analyse my interview data, and decided that the idiographic nature of interpretative phenomenological analysis (IPA; Smith, Flowers and Larkin, 2009) would be most sensitive to understanding the lived experiences of each participant's relationship.

3. Recruiting Participants

As I developed my research idea, I had several discussions with supervisors around the likelihood of successful recruitment. Compared to the general population, PWID over the age of 65 are reported to be five times more likely to have dementia (Strydom, Chan, King, Hassiotis & Livingston, 2013). According to the Alzheimer's Society (2013), over half of over 60s with Down syndrome have Alzheimer's disease. For adults with an ID other than Down syndrome, dementia affects 10% of 50 to 65 year olds, rising to 75% of all PWID over 85 years old. Based on this information, it was anticipated that there would be a number of PWID and dementia within the geographical areas of my recruitment, and therefore multiple staff members supporting each of these individuals, who might be eligible for inclusion. Informal discussions with ID organisations indicated that they did support PWID and dementia, and several service managers were keen to disseminate my recruitment packs.

Although this seemed encouraging, in reality, my early attempts to recruit attracted few participants. I continued to speak to service managers to ask them to further disseminate my recruitment information. On the request of some organisations, I attended team meetings at specific residences to discuss my research. Although I eventually reached my goal for the proposed sample (10 participants), my discussions with managers highlighted some potential barriers to achieving this target.

3.1. Barriers to the cascading of recruitment materials

The cascading of information to the direct support staff was less straightforward than I had anticipated. I contacted the main ID organisations within the catchment area of my research and spoke with organisational managers, who agreed to pass my recruitment packs on to the managers of the individual residences within their organisation. Organisation managers agreed that they would ask residence managers to hand packs out to their staff. However, due to not having direct contact with staff in the residences, it was unclear whether this information was reaching them. Indeed, when I contacted one residence manager directly (on the request of the organisation manager), she stated, “Oh, yes, I think I did see them, but I never got round to reading them and I think I threw them away.”

Jessiman (2013) considers some practical challenges of recruitment, including relying on “gatekeepers” (p.20) in the dissemination of recruitment information. In her article, entitled “To be honest, I haven’t even thought about it”, she highlights the value of researchers being more visible in the recruitment process, that is, meeting with gatekeepers to promote their enthusiasm. Unfortunately, given the number of organisations I recruited from, and the number of residences within each organisation, this was impracticable in the time constraints for completing my research. However, I have since reflected upon alternative methods I could have used to reach potential participants. One example was via a newsletter I learnt about on my ID placement (after gaining ethical approval and beginning recruitment). This was distributed to all ID organisations in one of my recruitment areas and could have been used to help disseminate my recruitment materials to a wider audience.

3.2. Barriers to volunteering

One participant, Maggie[2], held managerial duties alongside her direct support role. After the interview, she told me that she had distributed my recruitment packs to other support staff where she worked, but they had not wanted to take part. She added that they hadn't volunteered because "they didn't think they would know the right answers".

This led me to reflect on the use of the word "interview" in my recruitment packs. An interview for most people, I would imagine, is associated with being tested on your knowledge and skills, usually for the purpose of getting a job. For those not involved in qualitative research, I wondered whether the word interview did not accurately represent the reality of a research interview. I reflected on my understanding of this term prior to my research training as part of my undergraduate degree and doctoral training. I realised that it is only through my experience of academia that I have developed a working knowledge of such terms. When I was talking to Maggie about this, I talked about research interviews as being a "more informal conversation" about the topic, rather than a series of questions with right or wrong answers.

The NHS National Patient Safety Agency National Research Ethics Service (2011) guidance suggests the involvement of lay people in the review of participant recruitment materials to ensure language is accessible to all. I involved PWID in the design of my interview topic guide, which was of great value in understanding the importance of relationships in community residences, however it may have been worthwhile to also seek input regarding the accessibility of my recruitment documents, to ensure their clarity.

Another barrier to recruitment was described to me by some organisation managers when I followed up my initial request to disseminate recruitment packs. Some organisations agreed for potential participants to be interviewed within their working hours and others

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[2] All participant names are pseudonyms

apologised that they could not facilitate this, but agreed to cascade the recruitment information. I discussed my flexibility to meet participants at a time that was convenient to them, and some participants chose to be interviewed immediately before or after their shifts. However, I was informed by one organisation manager that he would not allow his staff any time out of work to attend an interview and that they wouldn't "want to do it in their own time because they won't get paid for it".

Initially I was somewhat frustrated with this, because it did not conform with my own enthusiasm for the research topic. I reflected on my reasons and motivations for conducting the research: to further my interest in this subject area; to fill a gap in the research; because I value the contribution of research and hoped to publish my findings in an academic journal; because I had designed the study and so was very invested in it; and finally as partial fulfilment of my clinical psychology doctorate. Conversely, I realised that there may be very little to motivate support staff, who work long shifts and unsociable hours, to take part.

3.3. Relating these barriers to my research findings

The barriers discussed above led me to reflect on how potential difficulties recruiting participants may also echo some of the findings from both my research paper, and my literature review (see Section 1 of this thesis). The literature review highlighted staff's perception that there was a distance between them and their managers, whereby their needs for training and support were not always recognised due to managers not being "in touch" with their roles. Both papers also highlighted staff's lack of confidence in doing things the "right" way in the absence of relevant training and support. Maggie's suggestion above that staff did not think they would "know the right answers" had some resonance with this lack of perceived confidence in ability. Furthermore, the suggestion from one manager that staff could not be released from work and would not want to do the research in their own time led me to consider whether managers did not appreciate the potential impact of dementia on their staff and therefore did not value the relevance of the research for their staff. Indeed, my participants appeared to value the research interview as an opportunity to talk about their experiences supporting PWID and dementia (as will be discussed below), which may provide further support for the research recommendations that managers offer support to staff to better understand their individual experiences of their role.

4. Researching an Emotive Topic

In this section I will discuss my reflections on researching an emotive topic, which was by far the most salient issue that arose from conducting data collection and analysis and an area which I believe warrants further discussion.

4.1. Impact on participants

When embarking on this research study, I was conscious of the potentially emotive nature of the topic. Dementia is a life-limiting condition (Kalsy-Lillico, 2014) and I was aware that research participants may be preparing for, or have already experienced, end-of-life care for the person they would be reflecting on in the interview. I carefully considered what I would do if participants became distressed within the interviews when writing my research proposal prior to gaining ethical approval. I also ensured that I provided contact details on participant information sheets for participants to use in the event that they felt distressed after the interview.

Indeed, many of my participants expressed emotion within the interviews as they considered their relationship with the person they supported as dementia progressed. Some participants were contemplating the person’s end-of-life, and for half of the participants’, the person had died within the previous five years. Most participants considered the losses they had experienced as the person’s personality was affected by dementia. It became apparent either within or after the interview that many participants had never had the opportunity to talk about their experiences in as much depth as they had in the interview. For participants who had experienced the person's death, the interview was often their first chance to reflect upon this, and some participants appeared to be processing the emotional impact of their loss within the interview, as illustrated by Andrea, who said this after starting to cry: "This is the first time I've spoke about him properly this is. So it's bringing a lot of emotions back."

As a clinical psychology trainee, I am trained in conducting both clinical work and research. The aim of a clinical interview is to help clients to better understand their experiences so that they can make changes, whereas a research interview aims to give the researcher a better understanding of the participants' perspective on a particular situation (Drury, Francis & Chapman, 2007). However, Drury et al. (2007) also highlighted the similarities between these activities and argued that participating in research interviews can be cathartic. This was supported by Dickson-Swift, James, Kippen and Liamputtong (2006) who interviewed researchers about their experiences of qualitative research interviews. This quote from one of their participants illustrates the potential therapeutic nature of research interviews for participants:

> I think they find it very therapeutic, especially if it's something that they haven't talked about before. They're in a situation where they are actually being invited to talk about it and that in itself acknowledges that it's an issue that's worth talking about and that's important. (p.858)

Indeed, the emotions expressed by my research participants seemed to be outweighed by the benefits of talking about their experiences. Some participants reflected on this after the interview had ended, as I debriefed them on the process. Despite maintaining the distinction between encouraging therapeutic change in clinical work, and gaining an understanding of a participant's perspective in research interviews, my dual role as a clinical psychology trainee enabled me to draw on my clinical skills to manage emotion within the interviews. On the contrary, Dickson-Swift et al. (2006) found that researchers with no therapeutic training felt ill-equipped to manage this therapeutic element and feared the potential to cause harm to participants who saw them as more of a therapist. Clinical psychologists and trainees can therefore be of great value in undertaking potentially sensitive research topics, and this argument will be expanded on below in relation to my personal response to the emotive stories.

4.2. Impact on the researcher

While I was well-prepared for the potential to manage participants' distress and incorporated this into my research protocol, I was less prepared for the emotional impact this research would have on me. Indeed, Dickson-Swift, James, Kippen and Liamputtong (2009) recognised a bias towards participants' emotions in research, with little focus on the impact on researchers. When writing my research protocol I ensured I had considered the potential risks to my physical safety, such as lone working, however it had not occurred to me that I may experience emotional distress too. Indeed, planning the research took a very practical focus; reviewing the available literature, preparing a research protocol, applying for ethical approval. At this stage, I was somewhat detached, and as yet unaware, of the stories I would be told by my participants.

I felt touched by the stories of my participants as they spoke about the meaning of the person's dementia and the associated losses they experienced. When participants cried as an expression of their emotions, I empathised with the emotional pain they were experiencing as they reflected on their relationship. This process was somewhat upsetting for me, and I remember consciously trying not to become tearful in one or two of the interviews. After the interview, I often continued to process my emotional response over the following hours and sometimes days. I often listen to distressing stories as part of my clinical role and seldom respond in the same way I did following these interviews. I realised that, even though some participants may have found it therapeutic to take part in the interview, it was difficult for me to hear emotional stories without being able to follow this up therapeutically.

I did my best to "reset" in preparation for the next interview so that I could focus on that participant's individual story. However, I was reacquainted with these emotions when later transcribing the interviews. Listening to the voices of my participants took me back mentally to the interview, and without the requirement to remain professional in my own home, I did find myself feeling upset or sometimes crying while hearing these touching stories again.

Dickson-Swift et al. (2009) apply the concept of "emotion work" (first developed by Hochschild, 1983) to the research process, arguing that researchers are commonly managing the emotions of their participants during interviews. Furthermore, it has been argued that listening to and transcribing interviews can also be an emotional experience (Dickson-Swift et al., 2009; Etherington, 2007). In recognition of the dearth of empirical evidence regarding the emotional impact of research on researchers, Dickson-Swift et al. (2009) interviewed 30 health researchers about their experiences of qualitative research interviews. The findings suggested that many of their participants had experienced strong emotions when researching sensitive issues. Like my personal experience, some of their participants described attempts to remain professional within the interview, but openly expressed their emotions in the aftermath. Dickson-Swift et al. (2009) go on to argue for the importance of considering the potential emotional impact research may have on us as researchers when we are planning the study, in order to prepare ourselves for this should it occur.

My personal response to listening to participants' emotive accounts led me to reflect on my own research planning process. Protecting research participants from any form of harm is built into the planning of a research project, and consideration of this is expected by research ethics committees (RECs) before approving the research (Dickson-Swift, James & Kippen, 2005). However, literature in this area suggests that RECs tend to focus more on the protection of participants than the protection of researchers. Having completed my REC application almost a year ago, I was curious to revisit this to see whether consideration of the emotional wellbeing of researchers was required on the form. Indeed, there was a question on the form which asked researchers to state the potential risks posed to them of conducting the proposed research and how such risks would be addressed. However, the only example offered on the form was to provide details of a lone worker plan, with no explicit mention of emotional risk. In this section of my application, I outlined how I would ensure my physical safety, but not how to manage the emotional impact of the research. This was not raised as a shortcoming within the ethics meeting, and consequently I did not consider it until I was in the interviews.

Dickson-Swift et al. (2005) found that explicit requests to consider the protection of researchers was absent from 34 out of 37 REC forms they analysed. They argued that REC forms should include a statement explicitly outlining the potential forms of risk that research may have on the researcher to ensure adequate consideration of such risks. Although it has been suggested that researcher safety is often considered in an “ad hoc contingent fashion once in the field” (Lee-Treweek & Linkogle, 2000, p.1), as was the case with mine, I think it is also important not to assign sole responsibility to the REC for identifying such oversights. However, the explicit inclusion of a section for potential psychological impacts of the research on the researcher would ensure such issues are adequately considered in the planning stage.

As a clinical psychology trainee, I have access to weekly clinical supervision on placement (British Psychological Society, 2010), whereby the emotional impact of therapeutic work with clients can be discussed and processed. Although I felt comfortable to discuss such issues with my research supervisors, I found research supervision to take a more practical focus. For example, I discussed issues regarding recruitment or considered how best to elicit relevant information from participants within interviews. This was reflective of my needs at the time in relation to being supported to conduct quality research. Although my research supervision took place less frequently than supervision in clinical practice, I did not experience this to be problematic or inadequate. Rather, I found that I had often self-resolved my emotions in response to the interviews before supervision meetings. I employed several strategies for doing so, such as writing in my reflective diary and maintaining self-care. Data analysis and discussion of my findings was another undertaking which helped me to process my emotions. The development of themes was somewhat cathartic, in that it offered some kind of structure to the experiences of my participants, therefore providing me with a framework within which to understand my own emotion.

On reflection, if I had considered the potential emotional impact of the research on me as a researcher, I would have addressed this within my research protocol and REC application and planned some more emotion-focused supervision after each interview. Nevertheless, Dickson-Swift et al. (2009) posit that some researchers are better prepared for managing the emotions elicited by research as a consequence of their specific discipline. I believe that clinical psychology trainees are well-placed to conduct emotional research due to the duality of their role in clinical and research settings. I think my experience managing emotion in relation to my clinical work, and processing this within clinical supervision equipped me with the skills to contain my emotion in a safe way throughout this research.

5. Conclusions

This critical appraisal focuses on the process of conducting qualitative research, from the inception of the research idea, to the reflections I have made since completing the research. I have discussed the challenges I have faced throughout these steps and considered how I might overcome such challenges in future research. I hope that these issues will be of utility to others considering qualitative research in the future. Despite these challenges, I have enjoyed conducting this research and it has contributed to my research, clinical and personal development. I feel privileged to have had the opportunity to hear the stories told by my participants and hope that the recommendations I have made can be used to support carers to continue to provide quality care to PWID.

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Section Four: Ethics Section

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Thesis Research Protocol – Version Two

Title of Research:	Staff Members' Lived Experiences of Their Relationship With An Adult With a Learning Disability Who Has Dementia
Name of Researcher:	Ailsa Lord
Field Supervisor:	[redacted]
Academic Supervisor:	[redacted]
Affiliation:	Lancaster University [redacted] [redacted]

Introduction

Background

Dementia is a condition that results from damage to the brain (Alzheimer's Society [AS], 2012; All-Party Parliamentary Group on Dementia [APPG], 2012). This neurodegenerative condition affects a person's cognitive functioning (Prince et al., 2013), memory, communication and behaviour (Biernacki, 2007). There are different types of dementia, the most common of which is Alzheimer's disease (AS, 2007; Snowden, 2010), followed by vascular dementia (Westerby & Howard, 2011), and it is also possible for a person to have "mixed dementias" (National Institute for Health and Care Excellence [NICE], 2011).

The number of people with dementia in the UK is increasing rapidly as a result of an ageing population, and it is predicted that the number of people with a diagnosis will increase from 800,000 (APPG, 2012; AS, 2012) to over one million by 2021 (AS, 2012). Dementia is also becoming increasingly common in individuals with learning disabilities as their life expectancy increases (Llewellyn, 2011, Prasher, 2005). People with learning disabilities are living longer as a result of a reduction in newborn and infant mortality and later health conditions, which has been attributed to improved medical interventions and healthcare, as well as better education and living conditions for people with learning disabilities (Prasher, 2005). Consequently, more adults with learning disabilities are surviving to develop dementias (Strydom et al., 2010). Indeed, certain genetic conditions associated with learning disabilities, such as Down Syndrome, are associated with a high risk of dementia, particularly Alzheimer's disease (Zigman et al., 2004) at an early age (Prasher, 1995).

The increasing prevalence of dementia in those with learning disabilities impacts on the provision of services and support for adults with a learning disability (Fahey-McCarthy, McCarron, Connaire & McCallion, 2009). Fahey-McCarthy et al. (2009) have argued that services are designed around adults with a learning disability who do not have dementia and therefore are not adequately equipped to support clients who do develop dementia. It has generally been agreed that people with learning disabilities who develop dementia are best placed within learning disability services, rather than services who specialise in dementia (e.g. Dodd, 2003; Kalsy et al., 2005; McCarron & Lawlor, 2003), and the concept of "ageing in place" (Kerr, Cunningham & Wilkinson, 2006; Watchman, 2003; Wilkinson, Kerr & Cunningham, 2005) advocates the adaptation of learning disability settings to accommodate a person's changing needs following the onset of dementia (Watchman, 2003). This has important implications for staff working in residential learning disability settings, as they may have little professional experience working with people with dementia (Wilkinson et al, 2005). Support staff have reported a need for dementia-related training to increase their confidence in working with this group (Fahey-McCarthy et al., 2009). Wilkinson et al. (2005) interviewed staff working with individuals with dementia and a learning disability in residential care home settings and identified the significant emotional impact this role can have. They found staff to be very committed to ensuring these service-users "aged in place" and raised the potential for staff to "burn out" if the demands of this role are not adequately met. Adults with a learning disability and dementia have been reported in the literature to require increased time from staff members (Janicki, Dalton, McCallion, Baxley & Zendell, 2005; McCarron, Gill, McCallion & Begley, 2005), which can have a detrimental impact on staff's wellbeing (Lloyd, Kalsy & Gatherer, 2008). For example, Lloyd et al. (2008) found that carers for adults with Down Syndrome and dementia reported greater emotional exhaustion than those caring for adult with Down Syndrome without dementia.

In their review of the literature on caregiving provisions for older adults with a learning disability and dementia, Courtenay, Jokinen and Strydom (2010) found 21 articles related to caregiving issues in people with a learning disability and dementia, and highlighted the need for further quantitative and qualitative research into carers' needs when working with this client group. They argued that the dissemination of such research will have a positive impact on this group of service-users. However, only five of the 19 articles that could be obtained employed qualitative methods and most focused largely on the impact of the more practical elements of caring for someone with a learning disability and dementia, such as staff working extra shifts and longer hours to best care for the person with dementia. These studies failed to consider the more relational aspects of this role.

Study Aim

This study aims to respond to the absence of research into the impact of dementia in adults with learning disability on their relationship with care staff. Using qualitative methods, the lived experiences of support staff who work in residential houses or supported living environments for adults with learning disabilities, with regards to their relationship with the service-user when they develop dementia, will be explored.

It is anticipated that this research will offer an insight into how the development of dementia in service-users with learning disabilities may impact on how staff negotiate and make sense of their relationship with the individual. It is well documented that the relationship between support staff and service-users is crucial in ensuring person-centred care, as highlighted by the recent events at Winterbourne View (Department of Health, 2012) and mid-Staffordshire NHS Trust (Francis, 2013), and therefore exploring relationships between staff and service-users with a learning disability and dementia may offer an understanding of how this might impact on their overall care. In addition, clinical psychologists are becoming increasingly involved in indirect work with staff teams in the learning disability field and the findings of this research would draw attention to the salient relational issues that arise for staff members when service-users develop dementia, which may offer guidance and recommendations for clinical psychologists in supporting such teams.

Method

Participants

It is aimed that between four and 12 participants will be recruited to take part in this research. It is commonplace for samples employed in Interpretative Phenomenological Analysis (IPA; described in “Proposed Analysis” section) research to be relatively small in order to focus on the issue being studied. Smith, Flowers and Larkin (2009) suggest between four and 10 interviews to be an appropriate number for a meaningful IPA study at professional doctoral level. They advise against attempting to maximise sample size, as this may be detrimental to the quality of the analysis.

The following information will be collected from participants recruited to the study: Age; gender; the length of time they have worked as a support worker with adults with a learning disability; the length of time they have worked with an adult with a learning disability and dementia; how many people with a learning disability and dementia they have supported; whether they have had any training related to dementia (and if so, what); and whether they currently support an adult with a learning disability and dementia.

Inclusion and Exclusion Criteria

Participants will be recruited from support staff working in residential houses or supported living services for adults with learning disabilities across [redacted]. If necessary (for example, due to recruitment difficulties), recruitment may be extended to other localities within [redacted] Where possible, participants will be recruited from a range of services.

In order to be included in the study, a potential participant must be a support worker who works in a residential house or supported living service for adults with a learning disability. They must have supported at least one adult with a learning disability who has been diagnosed with dementia and have known this individual for a minimum of six months. This relationship must have been within the last five years and does not necessarily have to be in their current place of work. These criteria aim to ensure that participants recruited to the study have or have previously had a relatively established relationship with the person with dementia for a reasonable amount of time that would allow them to reflect upon their experience of their relationship in enough depth to provide quality data.

Design

This study will employ a qualitative design, in order to gain in-depth accounts of participants' lived experiences of their relationship with adults with a learning disability and dementia.

Data Collection.

Data will be collected via semi-structured interviews in order to capture the subjective nature of lived experiences of a relationship with a person with a learning disability and dementia. Interviews will enable the researcher to approach the topic of interest using a flexible approach, allowing the participant to guide the direction of the interview to some extent (Smith et al., 2009).

Procedure

Recruitment.

The researcher will identify residential and supported living services in [redacted] areas via informal discussions with the respective [redacted] following which contact will be made with each service manager to provide an overview of the research project and the criteria for recruitment to the study (see Appendix A for email of support from one service manager of several residential homes). The researcher will offer to meet with service managers and/or teams if necessary, for example, at their team meetings. Service managers will be asked whether any staff who wish to participate in the study can be interviewed within their working hours or not, and whether interviews can take place at their place of work. They will be asked to disseminate recruitment packs to their teams, comprising a participant information sheet (Appendix B) and a cover letter with which includes an expression of interest slip (Appendix C).

Support staff who are interested in finding out more about the research will be invited to contact the researcher directly, by telephone or email, or return the expression of interest form by freepost, following which contact will be made by their preferred means. The research will be discussed in more detail with those interested in participating and they will be offered the opportunity to ask any questions. Potential participants will be informed that not everyone who volunteers will be asked to take part, so as to recruit from several services where possible. Those not invited to participate will be offered a summary report of findings on completion of the research. For those who are invited to participate, a mutually convenient time and venue for the research interview to take place will be arranged. Participants will be offered the choice to be interviewed at their place of work, within or outside of their working hours (if service managers have given prior agreement), or alternatively they can choose to be interviewed at [redacted] [redacted], where agreement has been given to use pre-bookable (see Appendix D). Participants will be advised that should they wish to be interviewed at their workplace, their anonymity as a research participant may be compromised, as other staff members and service managers are likely to become aware of the interview taking place (for example, gaining permission from managers to be interviewed within working hours or after shift). Should they have concerns about this, the researcher will remind them that they can be interviewed at [redacted], which would minimise the risk of their colleagues becoming aware of their participation. Participants who choose to be interviewed at [redacted] will be advised that, while minimal, there is still a risk that they might meet someone at this venue who is known to them, for example a colleague or client of theirs attending a meeting or appointment.

Sampling will be purposive; the researcher will aim to recruit participants from a range of residential and supported living homes to minimise the possibility of multiple participants talking about their relationship with the same person with dementia. However should there be difficulties in recruiting sufficient participants, it may be necessary to recruit more than one support worker from each home. Once sufficient participants have been recruited, those who express an interest will be informed that the recruitment has closed and thanked for their interest.

Interviews.

Before the interview begins, the participant will be given the opportunity to review the participant information sheet again and ask any questions. Participants will be asked to complete a consent form which includes a tear-off questionnaire regarding demographic and additional information (Appendix E) and begin the interview, which will be recorded.

Participants will be asked a series of open-ended questions aimed to explore their experiences of their relationship with a person with a learning disability and dementia, using a topic guide (an example of which can be found Appendix F) to provide structure. Interviews will last approximately one hour, however second interviews may be arranged at a later date if necessary. Should the participant wish to terminate the interview and withdraw from the research, the recording of their interview will be destroyed.

The recording device will be stopped at the end of the interview and the participant will be offered a debrief discuss their experience of the interview process or any concerns that they may have. Should participants experience any distress as a result of the interview, the researcher will attempt to answer any questions they have and signpost them to appropriate support. Participants will be reminded of the numbers they can contact should they experience any distress after the interview, which are included on the participant information sheet. The participant will be thanked for their participation and for the time they have given up to do so.

Service-User Involvement

The initial development of the research proposal for this study was reviewed in a Thesis Proposal Day organised by the Doctorate in Clinical Psychology department at Lancaster University, which included contributions from members of the Lancaster University Public Involvement Network (LUPIN). Following this, the proposed research was further developed.

In order to involve service-users in the development of this research in a meaningful way, the researcher has made contact with a local advocacy group called [redacted] with the intention of attempting to arrange to meet with some adults with learning disabilities to discuss the important aspects of staff –service-user relationships in residential and supported living environments. The aim of this, should it be possible to arrange, will be to inform and develop the example topic guide to ensure that the questions that will be asked are appropriate and relevant to the research aims. Ethical approval is not required for this, as [redacted] are contactable via a public website.

Proposed Analysis

IPA is a method of qualitative analysis which enables the researcher to gain an in-depth understanding of something which a participant considers to be significant to them (Smith et al., 2009). Using this approach, the researcher aims to interpret the participant’s own interpretation of their experience (Smith et al., 2009). Therefore, in this study, IPA will enable the researcher to gain an understanding of how participants have made sense of their relationship with a person with a learning disability who has developed dementia. As this will rely upon what the participant shares with the researcher, the researcher will be required to interpret the participants' reflections and own interpretations of the experience.

There is no single method for carrying out an interpretative phenomenological analysis of data, however the analysis will be guided by a six-step process outlined in Smith et al. (2009). This includes the development of emergent themes from transcribed interview data, which will be considered one interview at a time.

Theme development may be supported by the research supervisor and anonymised data may be taken to a peer support group, comprising fellow trainee clinical psychologists in the researcher's doctorate in clinical psychology cohort.

Practical Issues

Data handling.

This research involves the handling of participant identifiable data, that is, information with personal information about the participants recruited to the study. Data will be handled as follows:

1. Expression of interest slips (Appendix C), which will include contact details of potential participants, will be scanned as soon as possible after the interview and the paper copy will be destroyed. The scanned form will be password protected and stored on the researcher's password protected personal file space of the Lancaster University server until the research has been submitted, after which it will be deleted. This server is secure so files do not require further encryption. Expression of interest slips from those who decide not to take part will be destroyed as soon as possible.
2. The demographic and additional information tear-off slip will be detached from the consent form (Appendix E) after the interview. Responses to questions on the demographic and additional information questionnaires will be anonymised by

participant number or pseudonym and inputted into a password protected document on the researcher’s password protected personal file space of the Lancaster University server until the research has been submitted, after which it will be deleted (demographic information will be outlined in the research paper). Consent forms will be scanned as soon as possible after the interview and the paper copy will be destroyed. The scanned consent form will be password protected and stored on the researcher’s password protected personal file space of the Lancaster University server. On completion of the study (that is, once the research has been submitted as part of the Doctorate in Clinical Psychology), password protected scanned consent forms will be transferred to the Research Coordinator within the Doctorate in Clinical Psychology department via ZendTo file transfer software, which is secure. The researcher will send an email to the Research Coordinator with the password for the encrypted file, stating the end date of the research and the date which the file should be deleted (10 years after the research is submitted as part of the Doctorate in Clinical Psychology).

3. Digital recordings of interviews will be made using a portable digital recorder. It is not possible to encrypt these whilst they are on the recorder, however data will be transferred to the researcher’s password protected personal file space of the Lancaster University server as soon as possible after the interview, and deleted from the digital recorder. Once the data has been typed as a transcript and the initial analysis has begun, the audio file will be deleted. The research supervisor may listen to the audio recordings to support the researcher during the transcription, but these will be deleted as soon as possible. These will be sent to the research supervisor using ZendTo file transfer software, as detailed above. Transcripts will be saved in a password protected file on the researcher’s password protected personal file space of the

Lancaster University server. All participant identifiable information will be removed (e.g. pseudonyms used, place names changed). If these are shared with the research supervisor, they will be sent via ZendTo file transfer software, as detailed above. Any direct quotes used in the research report will be anonymised with any participant identifiable data removed. On completion of the study, password protected transcripts will be transferred to the Research Coordinator within the Doctorate in Clinical Psychology department as described above, and will be stored securely for 10 years after submission.

Interview venue and safety.

Participants will be interviewed either at their workplace or at [redacted] The researcher will follow the [redacted] Lone Worker Procedure [redacted] and the 'Guidance on safety in fieldwork' adopted by Lancaster University (Universities and Colleges Employers Association, 2005), where appropriate. If there are any issues relating to risk that the researcher is made aware of prior to scheduling an interview at the participant's workplace, a buddy system will be employed using a peer from the researcher's training cohort as a lone worker contact for the duration of the interview. They will be given a sealed envelope containing details of the arranged interview, and the researcher will contact them on completion of the interview. The envelope will be shredded. If the buddy does not receive confirmation that the interview has finished 45 minutes after the proposed completion time, they will attempt to contact the researcher via their mobile telephone. Appropriate emergency procedures will be followed if the buddy is unable to contact the researcher. This system will only be used when potential risks have been identified in advance. It should be noted that the workplaces of potential participants are likely to have other staff members on shift while the participant is being interviewed and therefore the potential risk to the researcher from clients is likely to be minimal.

When interviews are held at [redacted], a member of staff will be informed that the researcher is using the clinic room for a research interview and when they are due to finish. Participants will be advised that should they wish to be interviewed at [redacted], there is the potential for their confidentiality to be compromised, for example, if they were to report to reception stating they were here to participate in the research.

Costs.

Materials.

All documents related to this research will be printed/photocopied in the Doctorate in Clinical Psychology Department at Lancaster University, who will cover the costs. Any recruitment documents which require posting to services or participants will be sent from the department, and freepost return envelopes will be provided for participants to send their expression of interest forms back to the researcher. Digital recording devices and foot pedals for transcribing data will be borrowed from the department at no cost. A mobile phone will also be borrowed from the department in order to be contacted by potential participants or for the researcher to contact them. The cost of calls will be covered by the department.

Interview costs.

Room use at [redacted] will be provided free of charge. It is anticipated that interviews held at residential or supported living houses will also be at no cost. This will be established in initial meetings with service managers and where costs are indicated, interviews will be held in [redacted] to avoid this.

The researcher's travel costs to the interviews will be covered by the Doctorate in Clinical Psychology Department according to their expenses guidelines. If participants are travelling to the [redacted], they will be offered a reimbursement for their travel expenses. Those travelling by car will be offered 45 pence per mile, and public transport costs will be reimbursed on production of receipts/tickets, up to a maximum of £20 per participant per interview.

Ethical Considerations

Discovering potential malpractice.

If any participant discloses any information which indicates some malpractice within or related to their service, the researcher will contact their field supervisor [redacted] or the research supervisor [redacted], in the first instance and the appropriate steps to take will be discussed.

Fear of scrutiny of practice.

It is possible that support staff may have concerns that by participating in the research, their practice may be under scrutiny. Efforts will be made to reassure participants that this is not the purpose of the research and they will be reminded of the confidentiality agreement. They will be informed that confidentiality will be broken only if they disclose something which is of concern to the researcher, such as any potential harm to themselves or others, including the clients with whom they are working. In the event of such a disclosure, the researcher will discuss this with their field or research supervisor and the appropriate actions will be agreed.

Ensuring clients remain anonymous.

Participants will be reminded to make every attempt to maintain the anonymity of the person they are talking about within their interview, for example, by not using their names or other identifiable information. Participants may wish to choose a pseudonym for the client they are talking about. Any breaches of anonymity will be discussed with the participant to minimise any further breaches and pseudonyms will be used in transcriptions.

Managing participant distress.

Should any participants become distressed during the interviews, the researcher will draw upon their own clinical experience and training to support them where possible. Interviews will be followed in all cases by a debriefing, whereby the researcher will draw participants' attention to the participant information sheet which includes various contact details they can use should they feel distressed following the interview.

Project Management, Timescale and Dissemination

It is anticipated that ethical approval for the research will be applied for in early June 2014 and that data collection will begin in early July 2014 until October 2014, subject to timely ethical approval. Should amendments be necessary, recruitment will begin as soon as these have been agreed. It is expected that data will be analysed between August and November 2014 and the research paper will be prepared for submission as part of the researcher's doctoral thesis in May 2015. Should there be recruitment difficulties, the recruitment period may require extending and subsequent processes delayed.

Findings of the research will be presented as part of a Thesis Presentation Day held by the Doctorate in Clinical Psychology following submission and a summary report will be prepared for participants who requested one. Pathways to disseminate findings [redacted] will be agreed with those supporting and included within the research. The research paper will be prepared for submission to a relevant professional journal, such as Research in Developmental Disabilities, by August 2015.

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Appendices to Research Protocol

Appendix A: Email of support from a service manager of several residential houses

Appendix B: Participant information sheet

Appendix C: Cover letter and expression of interest slip

Appendix D: Email of support for use of rooms

Appendix E: Consent form and demographic and additional information questionnaire

Appendix F: Example Topic Guide

Appendix A

Email of Support from a Service Manager of Several Residential Houses

Re: Proposed Thesis Research

[redacted]

Sent:24 May 2014 07:50
To: Lord, Ailsa

Ailsa

Just to confirm after our conversation today myself and my staff team would be happy to support your thesis research entitled "Staff members lived experiences of their relationship with an adult with a learning disability who has dementia." We look forward to working along side you.

Many thanks

[redacted]

On 23 May 2014, at 15:47, "Lord, Ailsa" <a.lord@lancaster.ac.uk> wrote:

Dear [redacted],

Further to our discussions on the phone, would you be able to send me an email (including your [redacted] email signature or job title) confirming that you are happy to support my thesis research entitled "Staff members' lived experiences of their relationship with an adult with a learning disability who has dementia".

Thanks again.

Best wishes,

Ailsa
Ailsa Lord
Trainee Clinical Psychologist
Clinical Psychology
Faculty of Health and Medicine
Floor C
Furness College
Lancaster University
Lancaster
LA1 4YG

Email: a.lord@lancaster.ac.uk

Appendix B

Participant Information Sheet

Participant Information Sheet – Version 2 – 22.06.2014

Staff Members' Lived Experiences of Their Relationship With An Adult With a Learning Disability Who Has Dementia

Participant Information Sheet

Hello. My name is Ailsa Lord and I am conducting this research as part of my training on the Doctorate in Clinical Psychology at Lancaster University.

What is the study about and why have I been approached?

This research aims to explore the lived experiences of support staff who work in residential or supported living environments with adults with a learning disability, with regards to their **relationship** with the service-users when they develop dementia.

I have approached you because you work as a support worker in a residential or supported living home for adults with a learning disability, and you work/have worked with a service-user who has been diagnosed with dementia.

Criteria for taking part.

In order to ensure that you have/have had a relatively established relationship with an adult with a learning disability and dementia, which would enable you to reflect upon this experience in enough detail during the interview, there are some criteria for taking part:

- You must have supported an adult with a **learning disability** and **dementia**
- This relationship must have been for a **minimum of 6 months within the last 5 years**
- It is not essential that you still work with this individual (for example, if you or they have moved houses, or if they have passed away).

Please note that not everyone who volunteers will be asked to take part, as I hope to get a range of people to participate from different services. If you do not get the opportunity to take part, you are still welcome to receive a summary report of the findings once the study is complete – please let me know this when we speak.

What will I be asked to do if I take part?

If you decide to take part, I will arrange an interview with you, where I will ask you to talk about your experience of your relationship with an individual you have worked with who has a learning disability and dementia. I will ask that you talk about this person in a way that will minimise the chances of them being identified and maintain their confidentiality; this will include not using their name (however you could use a pseudonym).

I will record the interview and type it up as a transcript as soon as possible after the interview. The interview will last for around an hour, however we can be flexible if you need a break or we need to continue at a later point. It may be necessary to arrange a second interview, however I will discuss this with you at the time.

If your service manager agrees, I can come to your workplace for the interview*. Depending on the agreement with your manager, we may be able to do this during your shift, or we can do it just before or after. Alternatively, we can arrange the interview at [redacted]*, where reasonable travel expenses will be reimbursed. If you travel by car you can reclaim 45p/mile for your return journey, up to a value of £20 per interview. If you travel by public transport, the cost of your travel tickets will be reimbursed on production of receipts, up to £20 per interview.
**Please see section below regarding confidentiality.*

What will happen to the information that I give?
Once I have typed up your interview, I will consider the information you have given me along with that of other participants and write up and submit my findings as part of my thesis for the Doctorate in Clinical Psychology at Lancaster University. Following submission, I may present or share my findings with stakeholders who are supporting and/or involved in the research. I may also submit them for publication in an academic or professional journal and may present them at conferences. You are welcome to receive a summary report of the findings – please let me know if you would like me to send you this following submission.

Will my data be confidential?
Yes. Any data you provide as part of this study will be stored in a password protected file which will be saved in a password protected area of a secure server at Lancaster University; paper copies of your data will be scanned and destroyed. This includes any personal details you provide, the consent form and your interview transcript. As soon as I have typed your interview up, I will delete the audio file, which will be saved on the secure server and password protected after the interview. I may share your data with my research supervisor or other members of the Doctorate in Clinical Psychology as part of my research supervision, however your data will be anonymised. When I write my report, I may use direct quotes from your answers, however every effort will be taken to ensure that these will not identify you. Nobody from the service that you work in will see the data, however they may read the summary report at the end. On completion of the study, electronic copies of your transcript and consent form will be stored securely by the Doctorate in Clinical Psychology department at Lancaster University for 10 years.

Please note that there are some limits to this confidentiality: if I have concerns that you or someone else is at risk, I would need to break confidentiality and seek guidance from my supervisors, but I will tell you if I have to do this, where possible.

Taking part is voluntary. If you choose not to take part, or wish to withdraw your data after agreeing to take part, you do not need to give me a reason. You can withdraw up until the point of publication of the findings. However, if you decide to withdraw after I have anonymised your data and combined them with other participants' data, it might not be possible for me to remove them.

Please note that should you wish to be interviewed at your workplace, this may compromise your anonymity as a participant in this research, as you may have to ask your manager for permission to be interviewed. Should you prefer to be interviewed at [redacted], this risk will be minimised, however it is still possible that you may encounter someone you know there.

Are there any risks to taking part?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits?
Although you may find participating interesting, there are no direct benefits to taking part. It is anticipated that the findings of the research may enable the researcher to develop some ideas about how service-users and staff can best be supported when a service-user develops dementia.

How do I find out more or volunteer to take part?
You can find out more or express your interest in participating by completing the expression of interest slip, which is attached to the cover letter and returning this to me in the freepost envelope provided. Alternatively, you can contact me directly **by email** at a.lord@lancaster.ac.uk, or **by telephone**, on **[insert mobile number here]**. We can then discuss the research further, if necessary, and arrange an interview if you wish to take part.

Complaints or Concerns
If you wish to raise any concerns or complain about the research, you can contact Jane Simpson (Research Director), or Professor Paul Bates (Associate Dean for Research) using the details below:

Jane Simpson:
01524 592858
j.simpson2@lancaster.ac.uk
Doctorate in Clinical Psychology
Faculty of Health and Medicine
Floor C
Furness College
Lancaster University
Lancaster
LA1 4YG

Professor Paul Bates:
01524 593718
p.bates@lancaster.ac.uk
Associate Dean for Research
Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
Lancaster University
Lancaster
LA1 4YD

Please note, this study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee and approved by the University Research Ethics Committee at Lancaster University.

Resources you can use in the event of distress:
Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance:

Alzheimer's Society:	0300 222 11 22 / enquiries@alzheimers.org.uk (national helpline) 01524 550 415 / lancaster@alzheimers.org.uk (Lancaster and Morecambe) 01253 696 854 (Blackpool, Fylde and Wyre) / blackpool@alzheimers.org.uk
MENCAP Direct:	0808 808 1111 / help@mencap.org.uk
Samaritans:	08457 90 90 90 / jo@samaritans.org
Cruse Bereavement Care:	0844 477 9400 / helpline@cruse.org.uk

Thank you for taking the time to read this information sheet.

Appendix C

Cover Letter and Expression of Interest Slip

Cover letter – Version 2 – 22.06.2014

Doctorate in Clinical Psychology
Faculty of Health and Medicine
Floor C
Furness College
Lancaster University
Lancaster
LA1 4YG

Hello,

My name is Ailsa Lord and I am a Trainee Clinical Psychologist at Lancaster University. I am writing to you to tell you about some research I am doing as part of my doctoral thesis.

I am interested in learning more about the **relationships** between support workers in residential and supported living houses with adults with a learning disability who develop dementia. I believe that it is really important to hear the perspectives of staff working with this group in order to understand how best to support both staff and service-users.

If you have worked with **an adult with a learning disability who has been diagnosed with dementia**, I would be really grateful if you would consider participating in my research. I have enclosed some further information about the study in the Participant Information Sheet.

If you would like to express an interest in participating in my research or you want to discuss it in more detail before deciding, please complete the tear-off slip below and return it to me in the **freepost** envelope provided and I will contact you by your preferred means. Alternatively, you can contact me directly **by email** at a.lord@lancaster.ac.uk, or **by telephone**, on **[insert mobile number here]**.

Thank you for taking the time to read this information. I really value your support and I hope to hear from you soon.

Best wishes

Ailsa Lord
Trainee Clinical Psychologist

✂--

Name :…………………………………………………………………….. **Tel :**……………………………………………………………

Email address :……

Preferred method of contact (please tick): ☐ Telephone ☐ Email

Preferred times/days to contact you: ………

Signed: ……………………………………………………………………………………………………… **Date:** ………………………………

Appendix D

RE: Thesis Research

[redacted]

Sent:01 May 2014 09:20
To: Lord, Ailsa

Hi Ailsa,
To confirm, I have access to 2 bookable rooms on site here [redacted] so they are readily available (directly booked through myself). There are also additional rooms on site that [redacted] has access to which can be booked via reception.
Hope this helps.

[redacted]

[redacted]

[redacted]

From: Lord, Ailsa [mailto:a.lord@lancaster.ac.uk]
Sent: 01 May 2014 09:17
To: [redacted]
Subject: Thesis Research

Hi [redacted]

Can I just confirm that you are happy to support my thesis research [redacted] [redacted] [redacted], and that I can use a room at [redacted] if necessary to interview research participants? I just need written confirmation so I can include it in my ethics application.

Thanks

Ailsa

Ailsa Lord
Trainee Clinical Psychologist

Clinical Psychology
Faculty of Health and Medicine
Floor C
Furness College
Lancaster University
Lancaster
LA1 4YG

Email: a.lord@lancaster.ac.uk

RE: Thesis Research

[redacted]

Sent:01 May 2014 10:08
To: Lord, Ailsa
Cc: [redacted]

Hi Ailsa,
I am writing to confirm that I wholeheartedly support your research thesis and am happy for [redacted], obviously subject to all appropriate confirmation and consent procedures by relevant others. I am happy for you to use a room for interviewing as necessary.
All the best

[redacted]

From: Lord, Ailsa [mailto:a.lord@lancaster.ac.uk]
Sent: 01 May 2014 09:36
To: [redacted]
Subject: Thesis Research

`Warning: This message contains unverified links which may not be safe. You should only click links if you are sure they are from a trusted source.`

Hi [redacted]

Can I just confirm that you are happy to support my thesis research [redacted], and that I can use a room at [redacted] if necessary to interview research participants? I just need written confirmation so I can include it in my ethics application.

Thanks

Ailsa

Ailsa Lord
Trainee Clinical Psychologist

Clinical Psychology
Faculty of Health and Medicine
Floor C
Furness College
Lancaster University
Lancaster
LA1 4YG

Email: a.lord@lancaster.ac.uk

Appendix E

Consent Form and Demographic and Additional Information Questionnaire

Consent form & Demographic and additional information questionnaire – Version 2 – 22.06.2014

Doctorate in Clinical Psychology | LANCASTER UNIVERSITY

Staff Members' Lived Experiences of Their Relationship With An Adult With a Learning Disability Who Has Dementia

Consent Form

Thank you for agreeing to participate in my research study exploring staff members' experiences of their relationship with adults with learning disabilities after they develop dementia. Before we can go ahead with the interview, I would be grateful if you could complete the consent form below. If you have any questions before signing the consent form, please feel free to discuss with me (Ailsa Lord, the researcher).

☐ I confirm that I have read the information sheet and fully understand what is expected of me within this study.

☐ I confirm that I have had the opportunity to ask any questions and to have them answered.

☐ I understand that my interview will be audio recorded and then made into an anonymised written transcript, after which the audio file will be deleted.

☐ I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without this affecting my legal rights.

☐ I understand that if I choose to withdraw from the study after my data has been anonymised and incorporated into themes, it might not be possible for the data to be removed, though every attempt will be made to do so up until the point of publication.

☐ I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published.

☐ I consent to anonymised information and quotations from my interview being used in reports, conferences and training events.

☐ I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the researcher may need to share this information with her supervisor(s) and/or appropriate others.

☐ I consent to Lancaster University keeping copies of the written interview transcript and a scanned copy of this consent form securely for up to 10 years after the study has finished.

☐ I consent to take part in the above study.

Participant's Name______________________ Signature_____________________Date ____________

Researcher's Name______________________ Signature_____________________Date ____________

Demographic and Additional Information Questionnaire

I would be grateful if you could complete the following questionnaire. This information will anonymised and assigned your participant number or pseudonym, following which this paper copy will be destroyed.

What is your age in years?	
How long have you worked as a support worker with adults with a learning disability in total (approximate years and months)?	
How many people with a learning disability and dementia have you supported?	
Have you received any training related to dementia?	☐Yes ☐No
If yes, can you give some brief details of what this training involved?	
Do you currently support an adult with a learning disability and dementia?	☐Yes ☐No
If yes, how long have you worked with them (years and months)?	
Would you like a summary report of the findings?	☐Yes ☐No
If yes, I can send this by email or post. Please give your email address or postal address of where you would like it to be sent.	

Name: ....

Date: ....

Thank you for completing this questionnaire.

Appendix F

Example Topic Guide

Example Topic Guide – Version 2 – 22.06.2014

Doctorate in
Clinical Psychology

Staff Members' Lived Experiences of Their Relationship With An Adult With a Learning Disability Who Has Dementia

Example Interview Topic Guide

Introduction and Background

- Introductions – including name and role.
- Arrange reimbursement of expenses, if appropriate.
- Provide participant information sheet or read out if preferred. Answer any questions and address any concerns.
- Explain confidentiality procedure including exceptions to confidentiality, where guidance will be sought from supervisors.
- Explain that interview will last around an hour, but should the participant wish to take a break, this can be arranged. The participant can terminate the interview at any point.
- Check they still want to take part. If no, thank them for their interest. If yes, ask them to complete a consent form and demographic/additional information questionnaire. This has a box re: whether they want a summary report.

Interview

- Inform participant that you will start recording the interview now.

Possible questions:

Initial question:

- Do you have a particular individual in mind that you have worked with who has/had dementia? ***[Assign a pseudonym to protect the individual's anonymity.]***

Broad first topic questions (including prompts):

- Can you tell me about when you first started working with [pseudonym]?
    - Did you know the person before they were diagnosed with dementia?
- If so, can you tell me about your relationship with them before they were diagnosed?
- And after? What happened when they were diagnosed?

Follow up questions:

- If working with them now, where does dementia fit into your current relationship?
- What are the positives and negatives of your relationship with [pseudonym]?
- Which bits of your relationship with [pseudonym] are important to you?
- How do you think your relationship with [pseudonym] differs from your relationship with other adults with learning disabilities who do not have dementia?

Prompts for all questions:

- Can you tell me more about that?
- What do you mean by ………?
- Can you give me an example of that?

Debrief

- Stop the recording and inform the participant you have done so.
- Invite the participant to reflect on the interview in general. Any concerns/worries?
- Review contact details at the end of the participant information sheet and remind participant what they can do in the event that they feel distressed following their participation on the research
- Thank participant for their contributions to the research study and the time they have given up to participate.
- Ensure that any expenses have been paid or claim forms have been given.
- Ensure that participant has had the opportunity to express their interest in receiving a summary

Appendices

Appendix 4-A: Faculty of Health and Medicine Research Ethics Committee (FHMREC), Lancaster University - Application for ethical approval for research

Appendix 4-B: Feedback letter from FHMREC

Appendix 4-C: Letter of ethical approval from FHMREC and University Research Ethics Committee (UREC)

Appendix 4-A

Faculty of Health and Medicine Research Ethics Committee (FHMREC), Lancaster University - Application for ethical approval for research

Faculty of Health and Medicine Research Ethics Committee (FHMREC)
Lancaster University

Application for Ethical Approval for Research

Instructions

1. Apply to the committee by submitting
   - ✓ The University's Stage 1 Self-Assessment Form (standard form or student form) ***and*** the Project Information & Ethics questionnaire. These are available on the Research Support Office website: LU Ethics
   - ✓ The completed FHMREC application form
   - ✓ Your full research proposal (background, literature review, methodology/methods, ethical considerations)
   - ✓ All accompanying research materials such as, but not limited to,
     1) Advertising materials (posters, e-mails)
     2) Letters of invitation to participate
     3) Participant information sheets
     4) Consent forms
     5) Questionnaires, surveys, demographic sheets
     6) Interview schedules, interview question guides, focus group scripts
     7) Debriefing sheets, resource lists
2. Submit all the materials electronically as a **SINGLE** email attachment in PDF format. Instructions for creating such a document are available on the FHMREC website (http://www.lancs.ac.uk/shm/research/ethics/).
3. Submit one collated and signed paper copy of the full application materials. If the applicant is a student, the paper copy of the application form must be signed by the Academic Supervisor.
4. Committee meeting dates and application submission dates are listed on the research ethics committee website http://www.lancs.ac.uk/shm/research/ethics. Applications must be submitted by the deadline stated on the website, to:

   Diane Hopkins
   Faculty of Health & Medicine
   B03, Furness College
   Lancaster University, LA1 4YG
   d.hopkins@lancaster.ac.uk

5. Attend the committee meeting on the day that the application is considered.

1. Title of Project:

Staff Members' Lived Experiences of Their Relationship With An Adult With a Learning Disability Who Has Dementia

2. If this is a student project, please indicate what type of project by ticking the relevant box:

☐ PG Diploma ☐Masters dissertation ☐MRes ☐MSc ☐ DClinPsy SRP

☐ PhD Thesis ☐PhD Pall. Care/Pub. Hlth/Org. Hlth & Well Being ☐MD ☑DClinPsy Thesis

☐ Special Study Module (3rd year medical student)

3. Type of study

☑ Involves direct involvement by human subjects

☐ Involves existing documents/data only. Contact the Chair of FHMREC before continuing.

Applicant information

4. Name of applicant/researcher:
Ailsa Lord

5. Appointment/position held by applicant and Division within FHM
Trainee Clinical Psychologist

6. Contact information for applicant:

E-mail: a.lord@lancaster.ac.uk Telephone: [redacted]

Address: Clinical Psychology, Faculty of Health and Medicine, Floor C, Furness College, Lancaster University, Lancaster, LA1 4YG

7. Project supervisor(s), if different from applicant:

Name(s): [redacted]

E-mail(s): [redacted]

8. Appointment held by supervisor(s) and institution(s) where based (if applicable):
Research Tutor
DClinPsy
Lancaster University

9. Names and appointments of all members of the research team (including degree where applicable)
[redacted] (Field supervisor), [redacted]

The Project

NOTE: In addition to completing this form you must submit a detailed research protocol and all supporting materials.

10. Summary of research protocol in lay terms (maximum length 150 words).

Research into the impact of dementia in adults with learning disabilities on support staff focuses largely on the practical elements, such as the increased amount of time spent caring for these individuals and potential for stress and burnout as a result. There is a dearth of research into the impact of dementia in adults with learning disability on their relationship with care staff. This project aims to explore the lived experiences of support staff who work in residential houses or supported living environments for adults with learning disabilities, with regards to their relationship with the service-user when they develop dementia using a qualitative approach. It is anticipated that this research will offer an insight into how the development of dementia in service-users with learning disabilities may impact on how staff negotiate and make sense of their relationship with the individual.

11. Anticipated project dates

Start date: June/July 2014 End date: May 2015

12. Please describe the sample of participants to be studied (including number, age, gender):

Participants will be support workers working with adults with learning disabilities in residential or supported living homes. They will have worked with someone who has been diagnosed with dementia. It is anticipated that between four and 12 participants will be recruited to the study, based on the suggestion by Smith, Flowers and Larkin (2009) who advise against attempting to maximise sample size in Interpretative Phenomenological Analysis (IPA) studies as a means of quality assurance.

13. How will participants be recruited and from where? Be as specific as possible.

Participants will be recruited from residential or supported living houses across [redacted] [redacted] [redacted]. These services will be identified by informal discussions with the respective adult learning disability teams within [redacted] [redacted]. The researcher will contact the service managers of the houses to provide an overview of criteria for recruitment, and offer to meet with them/their teams if necessary. Service managers will be given recruitment packs to distribute amongst their teams containing instructions of how to participate. Potential participants will be invited to speak to the researcher before agreeing to take part, and a convenient day/time/location for the interview will be arranged for those who wish to go ahead.

14. What procedure is proposed for obtaining consent?

On the day of the interview, participants will be asked to read the participant information sheet (which they will have seen in advance) and asked to complete a consent form which includes a series of questions. Participants will be advised that they can withdraw up until the point of publication of the research study, however they will also be advised that this may not be possible to remove their data once it has been combined with that of other participants.

15. What discomfort (including psychological), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks.

- **Discovering potential malpractice.**
  If any participant discloses any information which indicates some malpractice within or related to their service, the researcher will contact their field supervisor [redacted] [redacted] [redacted] or the research supervisor [redacted] [redacted] [redacted] in the first instance and the appropriate steps to take will be discussed.

- **Fear of scrutiny of practice.**
  It is possible that support staff may have concerns that by participating in the research, their practice may be under scrutiny. Efforts will be made to reassure participants that this is not the purpose of the research and they will be reminded of the confidentiality agreement. They will be informed that confidentiality will be broken only if they disclose something which is of concern to the researcher, such as any potential harm to themselves or others, including the clients with whom they are working. In the event of such a disclosure, the researcher will discuss this with their field or research supervisor and the appropriate actions will be agreed.

- **Ensuring clients remain anonymous.**

Participants will be reminded to make every attempt to maintain the anonymity of the person they are talking about within their interview, for example, by not using their names or other identifiable information. Participants may wish to choose a pseudonym for the client they are talking about. Any breaches of anonymity will be discussed with the participant to minimise any further breaches and pseudonyms will be used in transcriptions.

- **Managing participant distress.**
  Should any participants become distressed during the interviews, the researcher will draw upon their own clinical experience and training to support them where possible. The interview will be followed in all cases by a debriefing, whereby the researcher will draw participants' attention to the participant information sheet which includes various contact details they can use should they feel distressed following the interview.

16. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, details of a lone worker plan).

Lone working – the researcher may hold interviews at the residential or supported living house or in a clinic room in [redacted] In both instances, the [redacted] Lone Worker guidance and the 'Guidance on safety in fieldwork' adopted by Lancaster University will be adhered to where applicable. It is possible that the researcher may encounter some risks by interviewing participants at their place of work. Such risks may include a client at the participant's place of work being aggressive or violent, etc. The researcher will ask participants about the potential environmental risks when arranging interviews at their place of work. It is not anticipated that there will be any such risks from participants. If there are any issues relating to risk that the researcher is made aware of prior to scheduling an interview at the participant's workplace, a buddy system will be employed using a peer from the researcher's training cohort as a lone worker contact for the duration of the interview. They will be given a sealed envelope containing details of the arranged interview, and the researcher will contact them on completion of the interview. The envelope will be shredded. If the buddy does not receive confirmation that the interview has finished 45 minutes after the proposed completion time, they will attempt to contact the researcher via their mobile telephone. Appropriate emergency procedures will be followed if the buddy is unable to contact the researcher. This system will only be used when potential risks have been identified in advance. It should be noted that the workplaces of potential participants are likely to have other staff members on shift while the participant is being interviewed and therefore the potential risk to the researcher from clients is likely to be minimal. When interviews are held at [redacted], a member of staff will be informed that the researcher is using the clinic room for a research interview and when they are due to finish.

Participants will be advised that should they wish to be interviewed at their workplace, their anonymity as a research participant may be compromised, as other staff members and service managers are likely to become aware of the interview taking place (for example, gaining permission from managers to be interviewed within working hours or after shift). Should they have concerns about this, the researcher will remind them that they can be interviewed at the [redacted], which would minimise the risk of their colleagues becoming aware of their participation. Participants who choose to be interviewed at [redacted] be advised that, while minimal, there is still a risk that they might meet someone at this venue who is known to them, for example a colleague or client of theirs attending a meeting or appointment.

17. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

There are no direct benefits to taking part in the study. Some participants may find it interesting to take part.

18. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

If participants are travelling to [redacted], they will be offered a reimbursement for their travel expenses. Those travelling by car will be offered 45 pence per mile, and public transport costs will be reimbursed on production of receipts/tickets, up to a maximum of £20 per participant per interview.

19. Briefly describe your data collection and analysis methods, and the rationale for their use

Data will be collected via semi-structured interviews with participants. The aim of the study is to explore participants' lived experiences of their relationship with adults with a learning disability and dementia, therefore a qualitative approach is the most appropriate method of achieving this.

Data will be transcribed following each interview by the researcher.

Transcribed data will be analysed using Interpretative Phenomenological Analysis (IPA), a qualitative method which enables the researcher to gain an in-depth understanding of something of significance to the participant. This method will allow the researcher to gain an insight into each participant's unique and personal experience of their relationship with the client.

20. Describe the involvement of users/service users in the design and conduct of your research. If you have not involved users/service users in developing your research protocol, please indicate this and provide a brief rationale/explanation.

The initial development of the research proposal for this study was reviewed in a Thesis Proposal Day organised by the Doctorate in Clinical Psychology department at Lancaster University, which included contributions from members of the Lancaster University Public Involvement Network (LUPIN). Following this, the proposed research was further developed.

In order to involve service-users in the development of this research in a meaningful way, the researcher has made contact with a local advocacy group called [redacted] with the intention of attempting to arrange to meet with some adults with learning disabilities to discuss the important aspects of staff –service-user relationships in residential and supported living environments. The aim of this, should it be possible to arrange, will be to inform and develop the example topic guide to ensure that the questions that will be asked are appropriate and relevant to the research aims. Ethical approval is not required for this, as [redacted] are contactable via a public website.

21. What plan is in place for the storage of data (electronic, digital, paper, etc.)? Please ensure that your plans comply with the Data Protection Act 1998.

This research involves the handling of participant identifiable data, that is, information with personal information about the participants recruited to the study. Data will be handled as follows:

1. Expression of interest slips, which will include contact details of potential participants, will be scanned as soon as possible after the interview and the paper copy will be destroyed. The scanned form will be password protected and stored on the researcher's password protected personal file space of the Lancaster University server until the research has been submitted, after which it will be deleted. This server is secure so files do not require further encryption. Expression of interest slips from those who decide not to take part will be destroyed as soon as possible.

2. The demographic and additional information tear-off slip will be detached from the consent

form after the interview. Responses to questions on the demographic and additional information questionnaires will be anonymised by participant number or pseudonym and inputted into a password protected document on the researcher's password protected personal file space of the Lancaster University server until the research has been submitted, after which it will be deleted (demographic information will be outlined in the research paper). Consent forms will be scanned as soon as possible after the interview and the paper copy will be destroyed. The scanned consent form will be password protected and stored on the researcher's password protected personal file space of the Lancaster University server. On completion of the study (that is, once the research has been submitted as part of the Doctorate in Clinical Psychology), password protected scanned consent forms will be transferred to the Research Coordinator within the Doctorate in Clinical Psychology department via ZendTo file transfer software, which is secure. The researcher will send an email to the Research Coordinator with the password for the encrypted file, stating the end date of the research and the date which the file should be deleted (10 years after the research is submitted as part of the Doctorate in Clinical Psychology).

3. Digital recordings of interviews will be made using a portable digital recorder. It is not possible to encrypt these whilst they are on the recorder, however data will be transferred to the researcher's password protected personal file space of the Lancaster University server as soon as possible after the interview, and deleted from the digital recorder. Once the data has been typed as a transcript and the initial analysis has begun, the audio file will be deleted. The research supervisor may listen to the audio recordings to support the researcher during the transcription, but these will be deleted as soon as possible. These will be sent to the research supervisor using ZendTo file transfer software, as detailed above. Transcripts will be saved in a password protected file on the researcher's password protected personal file space of the Lancaster University server. All participant identifiable information will be removed (e.g. pseudonyms used, place names changed). If these are shared with the research supervisor, they will be sent via ZendTo file transfer software, as detailed above. Any direct quotes used in the research report will be anonymised with any participant identifiable data removed. On completion of the study, password protected transcripts will be transferred to the Research Coordinator within the Doctorate in Clinical Psychology department as described above, and will be stored securely for 10 years after submission.

22. Will audio or video recording take place? ☐ no ☑audio ☐video
If yes, what arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

See number 3 in the above question.

23. What are the plans for dissemination of findings from the research?

Findings of the research will be presented as part of a Thesis Presentation Day held by the Doctorate in Clinical Psychology following submission and a summary report will be prepared for participants who requested one. Pathways to disseminate findings within [redacted] will be agreed with those supporting and included within the research. The research paper will be prepared for submission to a relevant professional journal, such as Research in Developmental Disabilities, by August 2015.

24. What particular ethical problems, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek advice from the FHMREC?

- **Breaking confidentiality**
  There are some circumstances whereby the researcher will need to break the confidentiality of the participants. Such instances include when a participant discloses that they or another person, including a client they are working with, is at risk of harm. Should such a situation arise, the researcher will speak to their field or research supervisor and appropriate actions will be agreed.

Signatures: Applicant: ……………………..……………………..

Date: ………………………………………………...

Project Supervisor* (if applicable): …………………………………..................

Date: ………………………………………………...

*I have reviewed this application, and discussed it with the applicant. I confirm that the project methodology is appropriate. I am happy for this application to proceed to ethical review.

Appendix 4-B

Feedback letter from FHMREC

Health and
Medicine
LANCASTER
UNIVERSITY

Our ref: FHMREC13070

12 June 2013

Ailsa Lord
Division of Health Research
Faculty of Health and Medicine
Lancaster University

Dear Ailsa,
Re: FHM Research Ethics Committee application for project titled: *Staff members' lived experiences of their relationship with an adult with a learning disability who has dementia.*

Thank you for sending in the paperwork for your application. We appreciated reading about the project and talking with you by telephone. We have a few minor concerns, and ask that you address the following in revising your application materials:

- **General**
  - Please remove duplicate documents when amending the application (pp 39 – 48)
  - Please ensure you use the current DClinPsy logo on your participant materials.
- **Application section 12**
  - Please add the minimum sample size and the rationale behind it.
- **Application section 14**
  - State a time limit for participants to withdraw their data.
- **Application section 15**
  - **Fear of scrutiny of practice:** you note that confidentiality will be broken if a participant discloses *something* which concerns you. Please clarify that this relates to potential harm to self or others.
  - Add here information about what support will be offered should a participant become distressed. We suggest you could draw on your own clinical training, offering a debriefing at the end of the interview, along with a debriefing sheet (which, if used, should be submitted along with your amended application).
- **Application section 16**
  - Please clarify the *sorts* of risks you envisage, and how you will ascertain whether any risks are likely to arise, adding in the information you gave to the committee.
  - Please clarify at what point you will set the 'buddy system' in train. Will you use it for every interview, or only where risks have been previously identified?
  - Ensure you leave a reasonable amount of time before the 'buddy system' is set in train, as interviews can sometimes run over.
  - Clarify how you will maintain confidentiality of participants when using a room [redacted], given that you will need to notify a member of staff that the room

is being used for project interviews. Alternatively, you should alert participants to the potential for decreased confidentiality.

- **Application section 19**
    - Clarify here whether your data will be transcribed, and, if so, who will be carrying out the transcription
- **Application section 21**
    - Further to our discussions regarding the use of a shared folder it transpires that there are technical issues which will not allow this at present, so you should proceed as outlined in your application.
- **Application section 24**
    - Please state here the circumstances in which you may have to break confidentiality (that is the 'limits to confidentiality', when you view that a participant has indicated they may cause harm to themselves or others).
- **Protocol**
    - P7 paragraph 1 where someone chooses to be interviewed in their workplace please provide further information about how confidentiality will be maintained. We suggest that you investigate this when setting up the interview.
- **Participant Information Sheet**
    - **Criteria for taking part**. Mention here what will happen should a potential participant not be chosen to take part in the study.
    - **Will my data be confidential?** Please make clear that confidentiality might be compromised should the interview take place in the workplace.
    - **Complaints section:** Please add Prof Paul Bates, Associate Dean for Research, Faculty of Health and Medicine (Division of Biomedical and Life Sciences), Lancaster University, Lancaster LA1 4YD (email p.bates@lancaster.ac.uk Tel: (01524) 593718) as an additional contact for complaints

In addition to the above a number of minor changes and typos are noted on your application form, attached with this letter. Please address these, as well as the matters above.

Ensure consistency between the application form, the Research Protocol and the supporting materials in line with the changes requested above.
Please use Lancaster University letter-headed paper for all participant materials
We ask that you attend to these in writing by (re)submitting to the FHMREC via Diane Hopkins (d.hopkins@lancaster.ac.uk) the application document and materials with any changes highlighted. If your responses to the above are satisfactory then approval will be recommended on Chair's action. If you have questions, please feel free to contact me.

Yours sincerely,

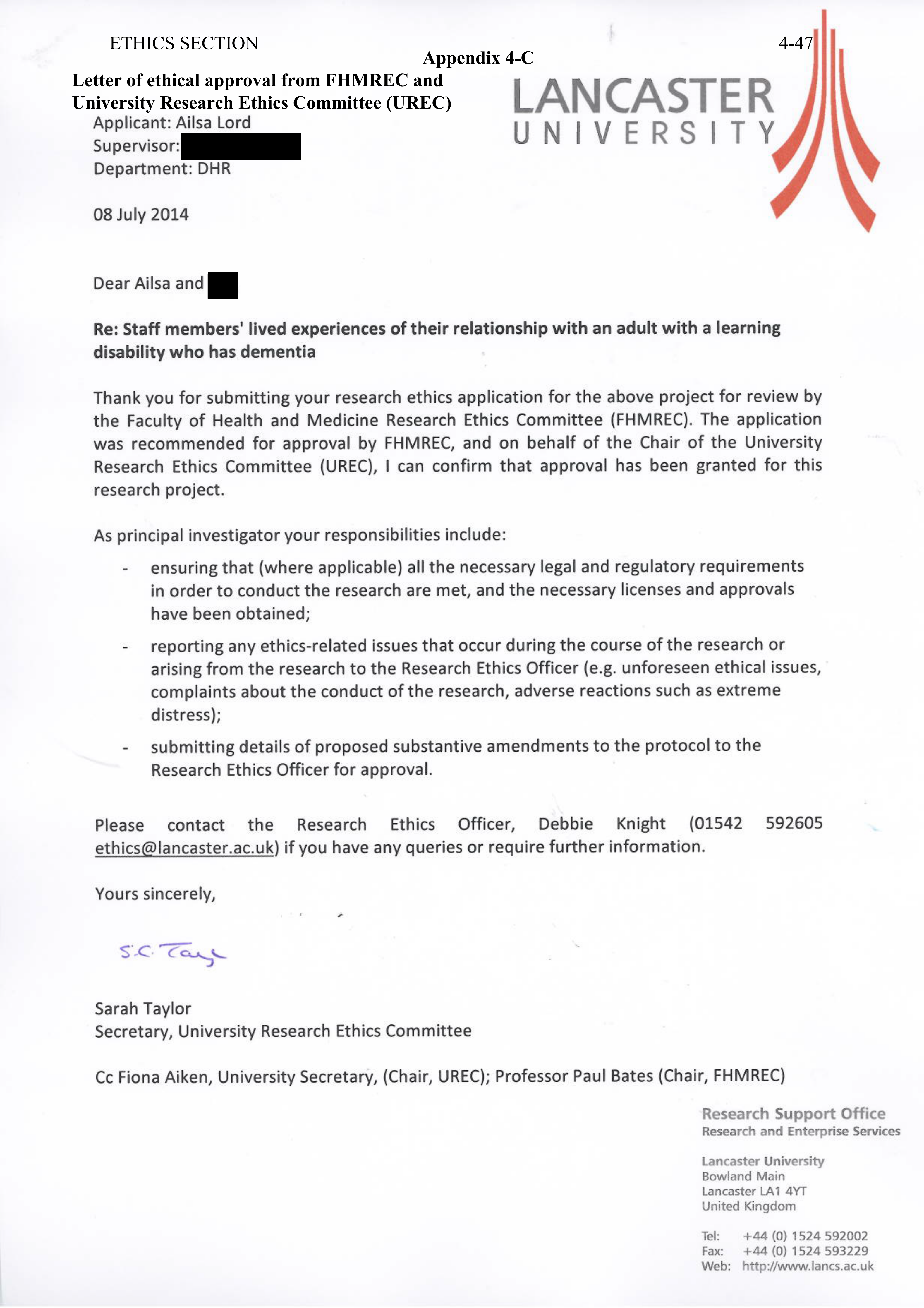
Paul A. Bates

Health and Medicine | LANCASTER UNIVERSITY

Prof Paul Bates
Chair of the Faculty of Health and Medicine Research Ethics Committee
Lancaster University

Appendix 4-C

Letter of ethical approval from FHMREC and University Research Ethics Committee (UREC)



LANCASTER
UNIVERSITY

Applicant: Ailsa Lord
Supervisor: [redacted]
Department: DHR

08 July 2014

Dear Ailsa and [redacted]

Re: Staff members' lived experiences of their relationship with an adult with a learning disability who has dementia

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee (UREC), I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the Research Ethics Officer, Debbie Knight (01542 592605 ethics@lancaster.ac.uk) if you have any queries or require further information.

Yours sincerely,

Sarah Taylor
Secretary, University Research Ethics Committee

Cc Fiona Aiken, University Secretary, (Chair, UREC); Professor Paul Bates (Chair, FHMREC)

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