The Experiences of Staff Who Support People with Intellectual Disability on Issues

About Death, Dying, and Bereavement: A Metasynthesis

Lord, A., Field, S., & Smith, I. C.

All correspondence should be sent to:
Ian Smith
i.smith@lancaster.ac.uk
Doctorate in Clinical Psychology
Faculty of Health and Medicine
Furness College
Lancaster University
Lancaster
LA1 4YG

Abstract

Background: Historically, people with intellectual disabilities have tended to be excluded from knowing about death, dying, and bereavement. Staff in intellectual disability services can play a valuable role in improving understanding of these issues in those they support. This qualitative metasynthesis aimed to understand the experiences of staff supporting adults with intellectual disabilities with issues of death, dying, and bereavement. **Method:** Thirteen papers were identified following a systematic review of six databases. **Results:** Three themes were developed following a lines-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. "A cautious silence: The taboo of death," was an overarching theme. **Conclusions:** A more open culture around issues of death, dying, and bereavement in intellectual disability settings is essential and could be promoted through staff training and support.

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

Introduction

Internationally, people with intellectual disabilities (PWID) are known to have a higher mortality rate (Florio & Trollor, 2015; Heslop & Glover, 2015; Lauer & McCallion, 2015; McCarron et al., 2015; Ouellette-Kunz et al, 2015) and die at a younger age (Bittles et al., 2002; Dieckman et al., 2015; Fearns et al., 2006; Heslop & Glover, 2015; Lauer & McCallion, 2015; McCarron et al., 2015; Public Health England, 2014) than those in the non-ID population. 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), and Dieckmann et al. (2015) suggests that such subgroups partly contribute to the lower overall life expectancy for PWID in general. Todd (2005) suggests that many PWID will end their lives in community residential settings and as their life expectancy gradually increases (Dieckmann et al., 2015), more of this group are experiencing bereavements than ever before (Dodd & Guerin, 2009).

It has been increasingly acknowledged that PWIDs' experiences of bereavement globally are similar to the general population (Dodd & Guerin, 2009; Harper & Wadsworth, 1993; Hollins & Esterhuyzen, 1997; McEvoy et al., 2012). Harper and Wadsworth (1993) suggest that expression of grief by PWID is not dependent on a full comprehension of the concept of death. This is often conceptualised using Piaget's (1960) framework, whereby an individual understands the causality, finality, cessation, universality and inevitability of death. Death concept varies widely in PWID and is thought to be better understood by higher functioning PWID (McEvoy et al., 2012). Stancliffe et al. (2016) found PWID to have a poorer comprehension of death concept than others. This supports McEvoy et al.'s (2012) findings that a full understanding of death was evident in less than a quarter of participants they interviewed about vignettes depicting death-related issues, with the majority (70%) having partial understanding. Earlier studies have also found that the majority of adults with

ID possess only partial comprehension of the concept of death (Dusart, 2008; Harper & Wadsworth, 1993; McEvoy, 1989; McEvoy et al., 2002).

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).

Similarly, PWID have often been excluded from discussions around their own mortality, terminal diagnosis (Tuffrey-Wijne et al., 2010), and terminal care (Bernal & Tuffrey-Wijne, 2008; Todd, 2004), with staff reportedly making the decision to exclude 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 timescale of the illness (Tuffrey-Wijne et al., 2013). Staff specific factors also influenced such decisions, including difficulties managing their own emotions or lacking knowledge about prognosis (Tuffrey-Wijne et al., 2013).

However, there is also evidence that being involved in bereavement rituals can be positive for PWID. Such involvement, including viewing the body, attending funerals, visiting the grave, and reminiscing about the deceased have been reported by PWID (McEvoy et al., 2012; McRitchie et al., 2014), and PWID have reported feeling proud to have been involved in such rituals (McRitchie et al., 2014).

McEvoy et al. (2012) and Tuffrey-Wijne et al. (2013) however emphasise that level of involvement should be responsive to individuals' preferences, as some may prefer not to

participate in some aspects. It is therefore concerning that less than half of those in McEvoy et al.'s (2012) study felt that they had received adequate bereavement support.

Staff in ID services should be well-placed to recognise and support issues of bereavement (Dodd & Guerin, 2009; Gilrane-McGarry & Taggart, 2007; Wiese et al., 2014) and PWID's own mortality (Wiese et al., 2014). However, to consider the most appropriate way for staff to provide such support, it is necessary to gain a better understanding of their experiences in supporting death, dying, and bereavement in ID settings.

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. Whilst several previous papers have looked at related topic areas (e.g. Brickell & Munir, 2008; Dodd et al., 2005; Dodd & Guerin, 2009; Dunkley & Sales, 2014; Tuffrey-Wijne, 2003; Tuffrey-Wijne et al., 2007a), no systematic review has yet been conducted with this specific focus.

In this review, we examine and synthesise the available qualitative research on the experiences of staff from ID services in supporting adults with ID in relation to issues of death, dying, and bereavement.

Method

Searching for studies

The search strategy for this metasynthesis was informed by guidelines proposed by Shaw (2012). The PRISMA 2009 checklist for the reporting of systematic reviews (Moher et al., 2009) also informed the design and structure of the review.

To develop a thorough search strategy, the constituent parts of the research question were determined. An adapted form of the SPIDER tool (Cooke et al., 2012) was used and

search terms for sample, phenomenon of interest, and research design were developed (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 August 2016. Free text search terms and database-specific subject headings were combined for each domain identified, using the Boolean instructor "OR". Free text 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 where a database enabled this limiter (PsychInfo, Academic Search Complete and CINAHL). The initial search yielded 722 papers (MEDLINE=128, PsychInfo=115, Academic Search Complete=157, CINAHL=109, EMBASE=75, Web of Science=138). 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. 118 papers remained after this initial review (MEDLINE=22, PsychInfo=26, Academic Search Complete=25, CINAHL=20, EMBASE=0, Web of Science=25). Only 37 of these remained once duplicates were removed.

Papers were included if they: (i) were in English; (ii) were published in a peer-reviewed journal; (iii) used qualitative methods and demonstrated qualitative analysis; (iv) reported the

experiences of staff supporting adults with ID with issues of death, dying, and bereavement (as opposed to their perceptions of PWIDs' experiences of these issues).

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 therefore included in the metasynthesis (see Figure 1 for a flow chart illustrating this search strategy).

<div align="center"><INSERT FIGURE 1 HERE></div>

Characteristics of selected studies

The key characteristics of the included papers are outlined in Table 4. The 13 papers (which are referred 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.

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Studies employed a range of qualitative methods, including questionnaire surveys with free text responses (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.

Appraising the quality of the selected studies

Quality was appraised so that it could be considered when synthesising the studies to ensure that interpretations were not biased towards weaker studies. The studies were appraised using the Critical Appraisal Skills Programme (Critical Appraisal Skills Programme [CASP], 2013), which is a tool aimed to evaluate the quality, validity and relevance of papers objectively according to 10 criteria. To add rigour to this process, papers were also CASP appraised by a peer. Any discrepancies between scores were discussed 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, which could range from 8 to 24. The mean CASP score was 19.5 (range=9-24). Some lower scores appeared to relate to poor reporting or journal word restrictions, rather than necessarily reflecting poor quality studies. The domain with the lowest scores (CASP question six) was that assessing whether the authors had addressed their relationship with participants.

<INSERT TABLE 5 HERE>

Metasynthesis

Qualitative metasynthesis is a method of systematic review aimed to deepen our understanding of a particular topic area by carefully integrating, synthesising and interpreting the findings of a number of qualitative studies (Erwin et al., 2011). First described by Noblit and Hare (1988), who use the term "meta-ethnography", this complex approach enables reviewers to go beyond the findings of the individual studies on a topic, identifying patterns, themes and contrasts, thus broadening and deepening the knowledge base in a topic area (Erwin et al., 2011). For a detailed discussion of the differences between qualitative metasynthesis and quantitative meta-analysis, see Erwin et al. (2011). The implementation of this method is detailed below.

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 "lines–of-argument" synthesis (LOA; Noblit & Hare, 1988, p.62) was implemented to develop themes. LOA synthesis goes beyond simply collating and summarising results of the individual papers, instead synthesising the individual findings in such a way that interpretations and inferences can be made about the topic in question as a whole (Noblit & Hare, 1988). Noblit and Hare (1988) describe this as "discover[ing] a 'whole' among a set of parts" (p63). In practice, this complex process generated new interpretations that could not be inferred from any of the papers in isolation thus providing a deeper insight into the topic area. The resulting themes identified aimed to be sensitive to inconsistencies and tensions across the studies, while capturing the breadth of findings.

Results

Three themes were developed through the synthesis of the 13 papers: (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 developed to represent what was learnt from the synthesis process. These will be discussed below, with supporting quotes[1] from the 13 papers. The contribution of papers to each theme is provided in Table 6.

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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 through a bereavement. Without direct experience, there was considerable uncertainty around talking about death: "...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 reinforced by assumptions about whether PWID should be engaged regarding issues of dying and bereavement, leading participants to avoid such conversations. There was 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." (S7, p.589). Another assumption was that bereavement support was limited by PWIDs' difficulty in expressing 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

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

about death, and consequently did not discuss a death with them: "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 dying 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. Actual bereavement 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": "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 dying, 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

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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: "[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 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 doing their best in the absence of feedback, training or support. Their uncertainty in supporting their clients was evident through their desire for policies and procedures to follow, which for some suggested a fear of the unknown: "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, such as 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 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 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 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 happen 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?" (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.

The commitment to promoting a "good death"

This theme captures participants' sense of privilege in supporting 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 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, 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) caused 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.

The grief behind the "professional mask"

This theme encapsulates the emotional impact on staff who supported PWID with issues of dying. 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.

Overarching theme – A "cautious silence": The taboo of death

The preceding three themes offer a LOA 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. 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 on whether or not they had encountered death within their role.

Despite this, most participants had skills but lacked confidence in supporting people 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 dying 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. Participants felt unable to discuss the impact of a person's death with their managers. This appeared to further reinforce the silence, because participants were "getting on with it" and the impact of death was therefore minimised.

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, there was a prevailing belief that they lacked appropriate knowledge, training, policies, and resources with which to confidently tackle this subject. This supports findings from MacHale et al. (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

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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 supporting 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 relating 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 et al. (1972, p.22-23). 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, 2010), 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 et al. (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; a perspective also offered by Weise et al (2015) in their discussion regarding how to involve PWID in issues regarding death and dying. 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 et al. (2011). Their commitment emphasised 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 the 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 et al., 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, 2010). However, disenfranchised grieving 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.

Clinical implications

The findings of this metasynthesis have highlighted several implications for clinical practice. Firstly it has identified a need for staff training 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 et al., 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 at 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 et al. (2012a; 2012b; 2012c) produced three accessible guides for supporting PWID with issues related to death, dying, and bereavement. The "Beyond Words" series also

include picture books addressing these issues (Hollins, Dowling & Blackman, 2014; Hollins & Sireling, 2014a; 2014b; Hollins & Tuffrey-Wijne, 2009).

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 should be guided by National Institute of Health and Care Excellence (NICE) commissioning guidance on end-of-life care in England (NICE, 2011).

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 the Methods, that some papers included in the metasynthesis were of poorer quality than others, according to the CASP ratings assigned. Consequently, 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.

Finally, while adhering to a systematic search procedure the first author was responsible for selecting and reviewing all included papers. However, this was closely supervised by the second and third authors to reduce potential bias.

Future research

This metasynthesis highlights several areas which warrant further research. The grief experienced by participants in these studies needs further exploration. A qualitative exploration of support staff experiences following the death of a PWID would provide further information on the issues 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 et al., 2007b) have used the Nominal Group Technique (Delbecq et al., 1975) to explore the perspectives of PWID in a meaningful and useful way. Use of this methodology to further understand PWIDs' knowledge of, and experiences being supported with, issues of death, dying, and bereavement, are certainly warranted.

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 metasythesis	Gender of participants included in metasythesis	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 clients' funerals; to understand what support these services offer to clients/staff/relatives regarding funerals and grief; to explore which elements of funerals are important to people with intellectual disabilities.	England	63	38	Not stated	Not stated	Learning disability 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 carers support people with learning disabilities 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 carers	Semi-structured interviews	Interpretative phenomenological analysis

S3	Hoover, Markell and Wagner	2005	To explore residential care providers' views regarding how they support people with intellectual disabilities 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 people with intellectual disabilities 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 carers in intellectual disability services and palliative care services in supporting clients with learning disabilities 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 people with intellectual disabilities 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 intellectual disability 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 clients with intellectual disabilities 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 clients in with intellectual disabilities living in residential care are affected by bereavement and how these clients 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 intellectual disabilities.	Semi-structured interviews	Interpretative phenomenological analysis

S9	Todd	2013	To understand how staff interpret/respond to the death of clients with intellectual disabilities; to understand how this is shaped by staff members' values.	England and Wales	22	22	Not stated	Not stated	Staff from intellectual disability service providers offering residential services to people with intellectual disabilities	Interviews	Thematic analysis
S10	Tuffrey-Wijne et al.	2013	To explore whether, and how, stakeholders disclose news of life-limiting illness and death to people with intellectual disabilities, 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 clients with intellectual disabilities 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 clients with intellectual disabilities 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 people with intellectual disabilities 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.
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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[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 (out of 24)	**18**	**20**	**14**	**9**	**18**	**17**	**19**	**23**	**23**	**21**	**23**	**24**	**24**

[3] Papers rated for each CASP question as weak (1), moderate (2) or strong (3)

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": No care for the carers?		✕					✕	✕	✕			✕	
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

Initial search using key search terms, and limited by English and peer-review where possible: **722 papers**

(MEDLINE = 128, PsychInfo = 115, Academic Search Complete = 157, CINAHL = 109, EMBASE = 75, Web of Science = 138)

↓

Titles, and if necessary, abstracts reviewed → **604 papers excluded** due to using non-qualitative methods or not being relevant to the research question

↓

Papers retained: **118**

(MEDLINE = 22, PsychInfo = 26, Academic Search Complete = 25, CINAHL = 20, EMBASE = 0, Web of Science = 25)

↓

Titles reviewed for duplicates

81 papers excluded due to being duplicates

↓

37 papers retained. Full texts reviewed for relevance to the metasynthesis and inclusion and exclusion criteria were applied.

26 papers excluded due to lack of relevance or failing to meet inclusion/exclusion criteria

↓

11 papers retained for inclusion in metasynthesis.

↓

Search of reference lists yielded an additional **2 papers.**

↓

Final number of papers included in metasynthesis: 13