Section 1: Literature Review

The views of adults with neurodegenerative diseases on end-of-life care: a metasynthesis

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Abstract

The purpose of this metasynthesis was to describe the views of adults with neurodegenerative diseases on end-of-life care. Thirteen qualitative studies were included and a metasynthesis design was employed to integrate the findings. Four analytical themes were identified; 1) Importance of autonomy and control; 2) It's the role of healthcare professionals to get the balance of information right; 3) Decision-making occurs in context; 4) Care can't meet all your needs. Participants' views were framed by the context of their lives and these shaped their engagement with end-of-life care. Palliative care would be beneficial in meeting the needs of adults with neurodegenerative diseases

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The views of adults with neurodegenerative diseases on end-of-life care: a metasynthesis

End-of-life care is a prevalent health care issue worldwide. Palliative care offers a theoretical model of end-of-life care for people with life-limiting conditions and is promoted by the World Health Organization (WHO) as the preferred approach (WHO, 2002). Conceptually, the aim of palliative care is to improve the quality of life of patients with life-threatening illneses and their families by providing compassionate care that emphasises the importance of attending to individuals' psychological and spiritual needs as well as the physical aspects of dying (Morrison & Meier, 2004). Accordingly, central importance is placed on the wishes of the dying individual. Effective palliative care has three main aims: management of physical symptoms and side effects; continuing communication of treatment goals between doctor, patient and family; and psychological, spiritual and social support for patient and family.

Despite the rapid growth of palliative care across the world since its conception as part of the modern hospice movement, death remains largely medicalised (Clark, 2002). As a result of medical advancement, life expectancy has broadly increased over time; however, it is not clear whether living significantly longer is associated with living better or diminished suffering. For instance, Zimmermann and Rodin (2004) argue that the "technological imperative" of medicine has resulted in depersonalised care. They propose that the only constraint on intervention in modern medicine is the sophistication of the technology, which results in a situation where life prolonging treatments are done because they are possible, rather than in the best interest of the individual. Congruently, Yuill (2015) argues that medical science has made it possible to sustain life beyond the point of desirability. Consequently, a strong argument has been made for increased quality rather than quantity of life being the overt goal of end-of-life care.

Nevertheless, end-of-life care is a contentious issue (Zimmermann & Rodin, 2004). Although there is agreement between healthcare professionals and patients that improvement in end-of-life care is possible and desirable, it remains unclear what quality care means conceptually to patients and their families, what role the state should play in end-of-life care and how best to evaluate 'good' end-of-life care (e.g. Earle, 2003; Teno, 2004).

Research has sought to improve understanding of quality end-of-life care. For example, a systematic review by Hinkle, Bosslet & Torke (2015) found that high quality, empathic communication, collaborative decision-making support and specific care measures that prepared patients for the end of life were associated with increased family satisfaction with end-of-life care. Similarly, a meta-analysis by Gomes et al. (2013) revealed statistically significant beneficial effects of home palliative care services compared to usual care on reducing the impact of symptoms.

Furthermore, Heyland et al. (2006) conducted a survey of people with chronic end-stage disease and their families and found that the most important aspects of good end-of-life care were trust in health care professionals, avoiding life-prolonging treatments where meaningful recovery was unlikely, open and honest communication, continuity of care and 'completing' life. This survey was based on qualitative accounts related to good end-of-life care, suggesting that qualitative research is consistent with the findings of quantitative research in this area.

Neurodegenerative diseases

A systematic review by Zimmermann, Riechelmann, Krzyzanowska, Rodin and Tannock (2008) demonstrated that palliative care approaches improve family satisfaction with care for people with chronic conditions. However, evidence further suggests that access to palliative care is predominantly restricted to people with cancer (Solano, Gomes, & Higginson, 2006).

Neurodegenerative diseases, which are largely adult-onset, including Alzheimer's disease (AD), Parkinson's disease (PD), Huntington's disease (HD) and motor neuron disease[1] (MND), are characterised by progressive loss of structure or function of neurons, including neuronal cell death. Each of these diseases is distinct but they share a number of characteristics, such as loss of functioning in a range of domains, and are thought to have cellular and molecular mechanisms leading to cell degeneration in common, such as protein aggregation and inclusion body formation (Ross & Poirier, 2004). It is estimated that, since 2002, chronic conditions (of which degenerative diseases are included) are the largest cause of death globally (WHO, 2008). Despite their capacity to cause significant morbidity and shorten life, neurodegenerative diseases are not typically associated with palliative care (Luddington, Cox, Higginson, & Livesley, 2001). Research suggests that the quality of end-of-life care for people with neurodegenerative diseases is often poor (e.g. Borasio & Voltz, 1997; McGarva, 2001). This is in spite of the fact that people with neurodegenerative diseases are often aware in advance that their cognitive abilities and capacity for communication will decline and for some (e.g. MND) the time from diagnosis to death is relatively short.

It is possible that there are significant challenges with the implementation of palliative care in this population. For example, historically palliative care has followed a cancer model. Disease trajectories for neurodegenerative diseases are more variable, ranging from years to decades, and so prognosis is uncertain (Goldstein & Morrison, 2013). A further barrier may be the beliefs and attitudes of healthcare professionals; for example, beliefs that palliative care should only be offered at the end stage of an illness, or negative attitudes due to the irrevocability of disease progression (Kristjanson, Toye, & Dawson, 2003), which may be conveyed to patients

[1] The UK term Motor neurone disease is used throughout this synthesis, which is also known as amyotrophic lateral sclerosis (ALS)

and families. Additionally, there may be issues with active decision-making as a result of capacity and ability to communicate diminishing over time (S. A. Simpson, 2007).

However, due to the broad scope of the definition of palliative care, it can in principle be integrated with curative treatment and need not preclude life-prolonging treatments. This, therefore, suggests that it is desirable for palliative care to be implemented as part of the routine care of people with neurodegenerative diseases. A systematic review (Siouta et al., 2016) indicated increasing appreciation for the value of integrated palliative care in patients with life-limiting non-cancer conditions and suggested the need for the development of standardised strategies so that barriers to implementing an integrated approach are lessened. This is congruent with the position of the WHO, which has indicated that the need for palliative care for people with life-threatening conditions begins at the point of diagnosis (WHO, 2002).

Comparable with end-of-life care, it is argued that treatments for neurodegenerative diseases are also highly medicalised. To illustrate, in relation to AD, Bartus (2000) argues that scientific interest in palliative treatments has declined and been superseded by efforts to understand the process of neurodegeneration through molecular approaches. In support of this, it is frequently presumed that biological factors are the primary causes of psychological problems in neurodegenerative diseases (e.g. Eccles, Murray, & Simpson, 2011; Matchwick, Domone, Leroi, & Simpson, 2014) and, accordingly, medical interventions are most frequently used to address them (e.g. Bonelli, Wenning, & Kapfhammer, 2004). However, their effectiveness has generally been found to be limited. For example, a systematic review by Drijgers, Aalten, Winogrodzka, Verhey and Leentjens (2009) found that there was insufficient evidence to support pharmacological treatment for apathy in neurodegenerative diseases.

Notwithstanding the promise of biomedical approaches, it is widely acknowledged that the psychological and social aspects of living with a neurodegenerative disease are as vital and worthy of attention as physical care. For example, in HD, Arran, Craufurd and Simpson (2014) found that a number of psychological factors were associated with higher levels of depression and these were more predictive of distress than more clinical variables (such as severity). Conversely, in PD, the results of an international survey reveal that the severity of disease and effectiveness of pharmacological interventions combined only accounted for 17% of the variance in health-related quality of life (Global Parkinson's Disease Survey Steering Committee, 2002). Similarly, a study by Ho, Gilbert, Mason, Goodman and Barker (2009) suggested that psychological variables were more useful than any other in predicting health-related quality of life in HD. This indicates that a psychological framework may be useful.

Despite the importance of qualitative research in understanding people's views, existing research on psychosocial aspects of neurodegenerative diseases is predominantly quantitative. Multidimensional constructs such as quality of life (Finlay & Dunlop, 1994) or coping are often quantified in attempt to measure subjective experiences (e.g. Chiò et al., 2004; Pace et al., 2009). This data may not therefore wholly reflect the experience of the individual. Despite this, qualitative approaches are well suited to exploring views and experiences (Smith, 2007) and there is a robust precedent for metasyntheses focusing on the needs and views of people in healthcare settings (e.g. Hodge & Horvath, 2011; Waibel, Henao, Aller, Vargas, & Vázquez, 2012).

It is important to understand the views of people with neurodegenerative diseases because research has shown that affected individuals, carers and families are generally aware of their needs and would wish to plan ahead (Kristjanson et al., 2003). It was decided that it was timely

and necessary to conduct a qualitative metasynthesis to explore the views of people with neurodegenerative diseases on end-of-life care because there is extant research in this area but to date there has been no qualitative review addressing this issue. Although individual qualitative studies may offer insight into the views of people with neurodegenerative diseases they are limited in scope and do not necessarily provide a comprehensive understanding. Synthesising extant research can enhance the generalisability of qualitative evidence (Sandelowski, Docherty, & Emden, 1997). Therefore, the purpose of this study is to review the empirical qualitative literature relating to the views of people with neurodegenerative diseases on end-of-life care in a systematic way. This will enable an overview of the existing research, potentially identifying areas for future study, illuminating service provision needs and offering ideas for good practice for specialist palliative care services.

Method

Research question

The review aimed to understand what the views of people with neurodegenerative diseases on end-of-life care are in end-of-life care. This question is expansive enough to encapsulate the phenomenon of interest and the synthesis of studies of different neurodegenerative diseases should yield fresh insights and conceptual development beyond that of reading individual studies.

Data collection

A systematic search of four electronic databases (Academic Search Complete, PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PsycINFO) was conducted in January 2016. Research was drawn from databases across psychological, social, medical and nursing disciplines to ensure a wide reach.

In order to identify search terms, the research question was separated into its essential parts: neurodegenerative diseases and end-of-life care. Search terms were generated by hand based on these two areas (see Table 1) and refined using the index terms for each database (for example, subject headings, APA descriptors, database thesauruses and the MeSH 'explode' function was used in databases where this was an option. The search terms were combined using the Boolean terms 'and' and 'or'.

Insert Table 1 here

Inclusion and exclusion criteria

The selected studies were screened using the following inclusion criteria: papers must (a) explore the views or experiences of participants who have an adult-onset neurodegenerative disease in relation to end-of-life care, (b) report findings of qualitative research using accepted qualitative methods of data collection and analysis, (c) be available in English and (d) be published in a peer-reviewed journal. No additional exclusion criteria were applied.

Neurodegenerative disorders are one of the most problematic classifications of disease (Du & Pertsemlidis, 2011). The definition of neurodegenerative diseases posited by Przedborski, Vila and Jackson-Lewis (2003, p.1) was used: "neurological disorders with heterogeneous clinical and pathological expressions affecting specific subsets of neurons in specific functional anatomic systems; they arise for unknown reasons and progress in a relentless manner". Therefore, neoplasm, oedema, haemorrhage, and trauma of the nervous system are not considered to be neurodegenerative disorders and were not included. Nor were pathologies in which neurons die due to a known cause, such as infection or poisoning. Multiple sclerosis was

included, however, as some evidence suggests that it is principally a neurodegenerative disease rather than an autoimmune disease (e.g. Chaudhuri, 2013).

An inclusive approach was taken to end-of-life care, to include anyone with a terminal or life-limiting condition that has become advanced, progressive and incurable, not only people in the final stages of life (Gysels et al., 2013).

The lead researcher initially assessed the titles and abstracts, and full text studies were obtained and screened if they appeared to meet the inclusion criteria. Studies that focused on the perspective of caregivers, family members, or healthcare professionals were excluded unless reported separately. Sandelowski & Barroso (2003) suggest a classification system for appraising the quality of analysis of research. Consistent with the recommendations of this system, 'no-finding' studies (e.g. articles consisting of uninterpreted narratives or diaries) and topical survey studies were excluded from the metasynthesis. To illustrate, a single case report by Mitsumoto & Rabkin (2007) was excluded, despite its use of rich quotes, because no qualitative analysis was evident and it was deemed a 'no-finding' study. Figure 1 summarises the application of the inclusion and exclusion criteria to the papers found.

Insert Figure 1 here

Critical appraisal

The quality of each study was appraised using the Critical Appraisal Skills Program (CASP) checklist for qualitative research (Public Health Resource Unit, 2006) to identify potential limitations. A three-point numerical scoring system was used, developed by Feder, Hutson, Ramsay and Taket (2006), whereby papers were given a score of 0-2 on each of the CASP's criteria out of a possible 10. The purpose of this appraisal was not to exclude studies, as

there is little rationale for doing so based on methodological quality (Bondas & Hall, 2007), but to give weighting to their contribution in the synthesis (Topcu, Buchanan, Aubeeluck, & Garip, 2016). All papers scored sufficiently highly and none of the papers were given less emphasis (see Table 2).

Insert Table 2 here

Characteristics of the selected studies

The thirteen selected studies had sample sizes ranging from 2-34 people. Diagnoses included HD, MND, MS, dementia and PD and participants varied widely in stage of disease. Seven of the selected studies noted that they used semi-structured interviews, one study used narrative interviews (employing a variety of modes of communication including email, diary and telephone), three studies did not detail the structure of their interviews, describing them as 'in-depth interviews', one study reportedly used 'episodic face-face interviews' and one study used autobiographies. Five of the selected studies used grounded theory, four studies used thematic analysis, two studies used narrative analysis, one study used 'manifest' qualitative content analysis, one study used the 'constant comparison method' and one study used a 'phenomenonological' approach to analysis.

The studies took place in a variety of settings, predominantly, individuals' homes, as well as hospitals, outpatient clinics, hospices and nursing homes. One study stated a private and quiet place of choice for participants.

Two studies used the same participants; however, they each provided a novel set of findings that were complementary as opposed to identical. Consequently, both studies were included in the metasynthesis. See Table 3 for more in-depth characteristics of the studies.

Insert Table 3 here

Data extraction, analysis and synthesis

An inductive thematic synthesis approach was used to synthesise the original content of the studies and produce a more advanced understanding through interpretive themes. The three conceptual stages of thematic approach to metasynthesis identified by Thomas and Harden (2008) were followed: the ‘line-by-line’ coding of text; the development of descriptive themes; and the generation of ‘analytical themes’.

Each paper was read and re-read so that the lead researcher became familiarised with and immersed in the data. Reflective notes were kept at this stage to enhance depth of understanding. The studies were then coded, much as they would be in primary qualitative research, to capture the themes within the original studies relating to the review question on people’s views on end-of-life care.

The codes were then analysed, identifying differences and similarities between them, to generate an initial set of descriptive themes. These descriptive themes did not attempt to reinterpret the primary findings; closeness to the original data sets was felt to be essential in this secondary analysis. These themes were considered to extract the meaning of studies in a consistent way that was close to the original interpretations of the respective authors.

Finally, more interpretative analytical themes were refined from the descriptive themes. These analytical themes are more tacit, abstract entities and attempt to capture the essence of the data (DeSantis & Ugarriza, 2000). This process can be seen as analogous to the development of 'third order interpretations' in meta-ethnography (Britten et al., 2002). The process and the contribution of each paper to each analytical theme is provided in Table 4.

Insert Table 4 here

Results

Four analytical themes were identified in the analysis of the interview data, which are detailed below with supporting quotations from the data.

Importance of autonomy and control

A strong sense of the importance of autonomy and control ran through participants' accounts. For example, participants wanted to take an active role in decision-making about their care. Although there was wide variation in individuals' wishes (for example, for life-prolonging treatments, for hastened death, or for preferred place of death), participants were clear that these views should be respected and they should be involved in reaching a final decision. "And I would like to know how it will be managed and what my choices are" (Whitehead, O'Brien, Jack, & Mitchell, 2012, p.372). A minority of participants across studies appeared to have completed advance care directives[2] to articulate and formalise their intentions regarding their care. However, a lack of awareness of advance care directives was also present across studies with many participants communicating general wishes about their future care without having this documented. "We're dealing with things as we have to, and it's probably not a bad way of going about it. And just thinking I'll worry about it when it gets here. I can't worry about it before" (Greenaway et al., 2015, p.1009).

Desire for autonomy and control occurred in the context of participants' feeling that they had reduced control over many aspects of their lives as a result of their illnesses. Participants were acutely aware of the progression of their neurodegenerative disease and spoke about this

[2] An advance care directive, also known as living will, personal directive, advance directive, or advance decision, is a legal document specifying what care an individual agrees to in the event they can not make decisions for themselves.

affecting their ability to make active decisions. For example, some people felt that their choices about medical interventions were restricted because of their condition. “It’s not a choice, you either use it or can’t breathe of a night, so there is no choice.” (Greenaway et al., 2015, p.1005). Conversely, other participants felt reassured by making active decisions about their care. “I felt absolutely no control so I said to them [healthcare professionals]…Now I’m able to sit down and discuss it [end-of-life care] with them… make decisions when you are in control [of care]” (Foley, Timonen, & Hardiman, 2014b, p.321).

Loss of autonomy was associated with diminished quality of life and meaningfulness.

> I asked about a possible trache and ventilator for the future. He said a definite ‘NO’, he wouldn’t advise it and neither would the other consultant there. The main reason was expense of care package. But what about what I want!!!! That didn’t seem to matter… Maybe he hopes by then I won’t be well enough to discuss it. I feel useless and as if my life isn’t even worth talking about (Whitehead et al., 2012 p.372).

It can be seen from this participant’s account that she did not feel included in decision-making, which affected her mood and self-worth.

Some participants questioned the value of life-prolonging treatments given the life-limiting nature of their neurodegenerative diseases, perceiving that interventions could potentially prolong suffering. This was seen as unacceptable and participants talked about disengaging from care, for example, by refusing life-prolonging treatments and supportive care, when this was anticipated. For this group, autonomy over when and how to engage with their care was more important than extending their life.

Congruently, difficult decisions about life and death accompanied EOL care. Euthanasia and assisted dying were options chosen by some participants in countries where these was legal,

and wished for in countries where these were not. Hastened death represented a relief from suffering for some participants as well as a way of taking control of their situation when it became unbearable by choosing the manner and time of their death.

> I have said for ages, that if I could go to bed tonight, and not wake up, I'd be happy. I'd take that… The end will be a big relief. Even though there is no pain, no physical pain, there is mental pain, and I'm not saying that I am looking forward to the end but when it comes it will be a relief, won't it? (Whitehead et al., 2012, p.375).

Conversely, euthanasia and assisted dying were antithetical to some people's principles and therefore rejected. A minority wished to preserve life despite their impending decline, although this group did acknowledge feeling disturbed by the idea of severe physical impairment. Nevertheless, it can be seen that self-determination was important for participants, regardless of their beliefs.

It's the role of healthcare professionals to get the balance of information right

This theme conceptualised the information needs of participants and their, often implicit, belief that health care professionals are responsible for meeting these. Many participants spoke about a lack of information about their care, which inhibited their ability to make fully informed choices. "I didn't get the brochures or anything from the doctors… there's really not much there to help" (Giles & Miyasaki, 2009, p.121). Similarly, some participants felt that there was a lack of awareness of their neurodegenerative disease, even amongst health professionals, which added to their feelings of frustration. Some participants talked about managing the lack of information from healthcare professionals by actively seeking out information (e.g. from the internet). In contrast, some participants felt that they had all the information they needed, which enabled them

to make confident decisions. “They covered everything I wanted to know and the questions they asked were the right questions” (Poppe, Burleigh, & Banerjee, 2013, p.3).

Generally, there was ambivalence within and across studies over how much information is enough. Many participants wanted information to be able to make decisions about their care but reported anxiety about the prospect of a bleak prognosis. Fear of confronting their potential deterioration and death meant that some participants rejected advanced care-planning discussions, finding them futile or dispiriting. This variability in individuals’ information needs illustrates the complex task facing healthcare professionals.

Most participants valued their experiences of advanced care planning, finding it a helpful experience that gave them important information, the opportunity to have important conversations with loved ones, alleviated their worries about their care in the future and reassuring them that their wishes would be honoured.

> I suppose really it was the wisest thing to do because there is no use leaving things like that too long before things are going to get worse. You don’t know what you are doing… I decided to make arrangements and things so if anything happens now they all know, what I want and what’s happening so it saves me worrying about it (Poppe et al., 2013, p.3).

However, although participants were aware of concepts such as advance care directives and euthanasia, many did not have an understanding of the associated requirements or practicalities and, as a result, their wishes for their future care were vague.

“We wondered sometimes if it is at all possible. We didn’t know if it might be possible to make arrangements now or in fact whether it is possible to make arrangements at all” (Booij, Rödig, Engberts, Tibben, & Roos, 2013, p.326).

Similarly, participants disclosed their reticence in discussing end-of-life care. Many participants expressed their wish to have open conversations about end-of-life care but not knowing what to ask for or feeling able to raise this difficult topic. Accordingly, their expectations of care were not met.

Participants wanted a trusting relationship with their healthcare professionals and felt more reassured about their care when this was realised. Trust was placed in healthcare professionals when support and empathy were offered as well as sensitivity to their needs. “I was concerned that it was actually something that would help me but could weaken my ability in the daytime. And it really reassured me that actually it would make it better. That was what I wanted to hear.” (Greenaway et al., 2015, p.1007). It is possible that trust is a key determinant of participants’ satisfaction and presupposes other factors that comprise good care. Noticeably, when trust was not present participants across studies appeared to be silent and disengage from their care. For instance, a number of participants relied on the expertise of their healthcare professionals and suggested that healthcare professionals should take responsibility for and guide their decision-making. However, a number of participants experienced the expertise of healthcare professionals negatively and reported feeling pressured into decisions by healthcare professionals. Worryingly, these participants did not communicate their wishes because of perceived bias of healthcare professionals. “I wouldn’t go to a doctor, because I feel that the doctor may be biased. […] I want a neutral person and that is either my wife or a notary or a solicitor” (Burchardi, Rauprich, Hecht, Beck, & Vollmann, 2005, p.70). This group believed that the medical precept to first do no harm would prevent healthcare professionals from honouring their wishes if they involved withdrawing life-prolonging treatments. This demonstrates how a lack of trust prevented people from fully engaging in their care.

Decision-making occurs in context

Participants across studies communicated the importance of contextual factors in their end-of-life care. Family, for example, played a central role in decision-making. Most participants saw their neurodegenerative disease in a family context and frequently discussed their preferences for end-of-life care with family members and came to decisions endorsed by the family.

A prominent desire for participants was not to be a burden on family members. However, it was also important for participants to 'be there' for families and support and be supported by them. This demonstrates the complexity of decision-making. Family could be supportive but also demanding and participants often struggled to balance their personal needs with those of the family unit. At times this resulted in complex emotions and participants feeling restricted in their decision-making about care. For example, on considering assisted suicide one participant commented:

> I had to consider my family and the implications. It's like a suicide… the pebble in the water. It spreads out. It affects so many people, and I suppose a lot of family, like with suicide, they get angry that you were selfish (Foley, Timonen, & Hardiman, 2014a, p.72).

Family influenced not only decision-making but practical care. For example, some participants refused carers because family members occupied that role. These participants spoke about the importance of reciprocal family support.

Alternatively, where participants had no family to take into account, this influenced their choices. "You see, I don't feel I have the need to hang on at any cost. If I had a husband, wife, children, it might be different. So I'm free to make the choice." (Foley et al., 2014a, p.72).

Another important contextual factor was participants' perceived status in comparison with others. Frequent social comparisons were made in order to form opinions on care. These were often first-hand experiences, such as family members' experiences of the end stages of neurodegenerative disease. "Not the way my mother suffered." (Booij et al., 2013, p.326). Having witnessed a parent or other family member affected by the same neurodegenerative condition seemed to shape participants' wishes for end of life.

The variability of disease progression complicated decision-making for participants. Many participants were acutely aware of situations, points in their trajectory, that they felt would be unbearable and lead them to seek means to hasten their death.

> …As soon as I become dependent on others, then it is time to pull the plug. When I am not able to eat independently or be independent, that is unacceptable. If my quality of life diminishes to a point that I become dependent, then I quit (Booij et al., 2013, p.326).

The concept of time therefore influenced participants' views on EOL care. Some participants made the conscious choice to 'live in the moment', which meant decisions on interventions represented that particular situation in time. However, participants were cognisant that they might change their mind in the future and revisit these decisions. "I was going to write a living will but I've decided with my GP (general practitioner)[3] now that there's no point really, if I wrote a living will now you might want to change your mind."

Some participants held on to hope that the future might hold different options for care. This sense of hope sustained them in adjusting to the ramifications of their neurodegenerative diseases and engaging with their EOL care. "[I've] just got to stay fit and healthy and exercise, take my medication and hope… they have some luck with the stem cell testing" (Hudson, Toye,

[3] A general practitioner, also known as a family physician or primary care physician is a medical doctor who works in the community and takes a holistic rather than specialist approach to treating illnesses.

& Kristjanson, 2006, p.89). This quote illustrates how some participants were hopeful for future recovery. This contrasts with participants who had come to terms with the prospect of dying, some of whom had advance care directives in place stating their wishes for specific eventualities.

Care can't meet all of your needs

Participants described varied and individualised care needs, including emotional, physical and practical support. Often the care received was inadequate and viewed as difficult to access and a demanding experience. For example, the quality of interaction with healthcare professionals was sometimes poor and consequently a barrier to care. "And now I get pats on the cheek or, worst of all, on the head, like a child. So I hate it. That patronizes compassion. So far from compassion and empathy" (Rosengren, Gustafsson, & Jarnevi, 2015, p.79).

Often the promise of care was different to the reality and participants were left disappointed by the service they received. One participant spoke about how support groups, designed to provide psychosocial support, were unhelpful.

> I guess I don't really need to be around people like that at this stage… what are you going to do? Sit around and talk about how much you shake at night… it might tend to be a little depressing for the type of person that I am at the moment (Hudson, Toye, & Kristjanson, 2006, p.90).

Accordingly, specialist support services were highly valued, where healthcare professionals were well informed about their disease and able to provide continuity of care. "If I have any questions I visit the professor. And my GP, he doesn't really know about the disease" (Booij et al., 2013, p.328). "I have all the information from the MS Society, what's the best brand of car, lift, everything, grants…" (Wollin, Yates, & Kristjanson, 2006, p.23).

Often negative emotions were associated with the inadequacy of care. However, many participants seemed resigned to the fact that care could not meet all of their needs. They managed this shortcoming by selecting certain needs for professional care to address, while leaving others for family and friends to attend to. “I have already started to move out of my body. I’m moving up in the head instead. There I have my brain and my senses. The care and concern for my body, I leave to others.” (Rosengren et al., 2015, p.79).

This is further evidenced by participants’ assumptions that it is not appropriate to discuss certain concerns with healthcare professionals. To illustrate, some participants expressed a need for meaningfulness. This involved staying connected to other people and one’s own values. This was least commonly met by healthcare professionals and perceived as an inappropriate conversation topic.

> Those are pretty private things, like attitude towards life or further progress or whatever, and all those things you can talk about for hours, and I think that’s why the doctor doesn’t even bother getting into all that. Instead it’s just acute problems, and that was it (Galushko et al., 2014, p.278).

Many participants expressed a wish to die at home. For them, home was a meaningful place of care where family could support them and sadness was expressed at the thought of this not being possible. “With a tracheostomy, I’m stranded to a nursing home.” (Lemoignan & Ells, 2010, p.211). This demonstrates how participants questioned the meaning of interventions and made decisions about them based on their own values and goals.

Discussion

This synthesis developed insight into how people with neurodegenerative diseases viewed end-of-life care. Participants’ views appeared to shape their engagement with end-of-life care. No

claims of generalisability are made for the entire population of people with neurodegenerative diseases, yet the views within and across studies and disease conditions were remarkably similar.

The themes ‘Importance of autonomy and control’ and ‘It’s the role of healthcare professionals to get the balance of information right’ are consistent with extant research into patient preferences for healthcare. A systematic review by Kiesler and Auerbach (2006) confirmed that patients vary in how active a role they play in their healthcare and how much responsibility they wish to take over decisions made. Moreover, when the interactional styles of healthcare professionals and their patients do not align, outcomes such as effectiveness of treatment and patient satisfaction are negatively affected. The researchers suggest that healthcare professionals should not interact with patients in a rigid, standardised way but in a manner that matches patients’ preferences for information and involvement in decision-making. The finding of this metasynthesis that many participants were dissatisfied with the information given about their end-of-life care fits with research suggesting that healthcare professionals tend to be poor at communicating about end-of-life issues (Milberg & Strang, 2000).

Empirical evidence on neurodegenerative diseases supports the significance of autonomy and the notion that patients wish to be informed and actively involved in their care (e.g. Joffe, 2003; Tramonti, Bongioanni, Di Bernardo, Davitti, & Rossi, 2012). For example, focus groups revealed that for people with MND, feeling in control of care is of key importance (Cooney & Weaver, 2012). Similarly, lack of information has been found to be a barrier to effective care of people with neurodegenerative diseases (Kristjanson, Aoun, & Yates, 2006). However, it is noteworthy that some people want little or no role in decision-making (Benbassat, Pilpel, & Tidhar, 1998; Say, Murtagh, & Thomson, 2006).

Congruently, a minority of participants in this synthesis preferred healthcare professionals to make decisions about their care. It is possible to view this in a positive way, as individuals paradoxically exercising their autonomy and control by giving their responsibility for decision-making to healthcare professionals s. However, Rodin, Timko and Harris (1985) suggest that people who perceive less self-control tend to take less accountability for their health, be less likely to make use of health protective behaviours and have lower immunological response.

Locus of control, a construct from Rotter's social learning theory (1954), may offer a useful perspective. Levenson (1973) distinguished three sources of control: internal, powerful others and chance. A narrative synthesis by Eccles and Simpson (2011) suggested that wellbeing was associated with greater perceived control over life and that older people viewed their health as being controlled by powerful others such as doctors more than younger people. Age and perceived control may therefore account for the differences observed in this synthesis.

This corresponds with one of the principles of self-determination theory in health contexts (Deci & Ryan, 2008), which proposes that increasing an individual's autonomy and competence will facilitate internalisation of health protective behaviours and lead to behaviour change. Consequently it is argued here that, although different people may enact autonomy in different ways, a shared decision-making paradigm is preferable, where patients and professionals make decisions together on the best available evidence (Stiggelbout et al., 2012).

The theme 'Decision-making occurs in context' fits with previous work demonstrating that families are often aware of their needs and value planning for the future (e.g. Dawson, Kristjanson, Toye, & Flett, 2004). Foley (2014a) argues that often research individualises people's trajectories through terminal illness, divorcing their views from their social context.

Illness is positioned at an individual level whereas it may be more helpful to view neurodegenerative disease at a family level. This assertion is supported by research by Maxted, Simpson and Weatherhead (2014), which explored HD in family dyads. The findings suggested that the family members, who reported changes in identity and role, experience the impact of the condition. Additionally, a comprehensive review of MND family caregivers by Aoun et al. (2013) found that MND family caregivers experienced considerable distress and emphasised the need for psychosocial support for caregivers.

Research suggests that stage of disease is important, particularly in relation to desire for hastened death. For example, Paulsen, Hoth, Nehl and Stierman (2005) suggest that a critical period for HD is just before diagnosis and also when the affected individual feels they are about to lose their autonomy. It is possible that this contextual factor accounts for the variance in views across studies in the synthesis. Disease stage is also relevant because cognitive impairment is prevalent in neurodegenerative diseases. Some studies show that this happens earlier in disease trajectory than previously thought (e.g. Patti et al., 2009). Therefore, where possible, discussions about care should be facilitated early.

Social comparison was largely a negative experience for participants. The consequences of social comparison processes have been found to be determined largely by the degree of control individuals feel they have (Michinov, 2005), with upward comparisons producing a more positive effect when an individual perceives they have the ability to significantly alter events. This suggests that participants may have perceived themselves to have low self-control.

This fits with the concept of ‘possible selves’, coined by Markus and Nurius (1986). The term refers to an individual’s ideas of what s/he might become. The authors suggest that possible selves arise from social comparisons of one’s thoughts, feelings and behaviours to those of

salient others. Using this conceptual framework, participants who witnessed the decline of a close family member may have been confronted with their 'feared selves'. Consistent with self-regulation theory (Cameron & Leventhal, 2003), attempts to avoid similar situations may therefore be a way of minimising the impact of perceived threat. Similarly, the participants who hoped for a cure in the future did not have vague ideas of future medical advances but held a strong image of their 'desired selves' as recovered. This theory is supported by a study by French, Sutton, Marteau and Kinmonth (2004) exploring the effect of providing social comparison information on risk perception. It was found that positive comparisons lowered perceptions of risk compared to unfavourable comparisons and no social comparison information.

The final theme 'Care can't meet all your needs' attempts to capture the complex and variable needs of participants as well as their implicit understanding that these needs could not be fully met by care. The inadequate care described by participants mirrors the experiences of people with neurodegenerative diseases represented in empirical literature. For example, families of people with dementia frequently complain of insufficient symptom control and inadequate advance-care planning (McCarthy, Addington-Hall, & Altmann, 1997). In support of participants' appreciation of specialist services, research by van der Eijk, Faber, Al Shamma, Munneke and Bloem (2011) found that focus groups of patients with PD valued PD expertise in healthcare professionals. Similarly, best practice guidelines in relation to care for people with neurodegenerative diseases, such as the UK National End of Life Care Intelligence Network framework (2010), advocate a multidisciplinary approach.

The shortcomings in care identified by participants were largely related to their psychosocial needs rather than unmet biological or medical needs. Despite the widespread

acceptance of the biopsychosocial model of health (Engel, 1980) and subsequent move towards the delivery of holistic healthcare (e.g. in European and USA healthcare), Brown, Alaszewski, Swift and Nordin (2011) argue that the purpose of medicine is still perceived to be to correct the 'problematic body'. Likewise, for HD, Nance (2007, p.176) states that "the role of the physician is to identify patient symptoms for which there are medical treatments, and to write prescriptions for the appropriate medications", while acknowledging that most doctors take a broader role.

Evidence suggests that this conceptualisation is at odds with the needs of patients. For example, studies by Ho, Gilbert, Mason, Goodman and Barker (2009) and Simpson, Lekwuwa and Crawford (2014) found that mental health variables were more influential than physical ones in determining health-related quality of life in people with PD. Furthermore, Chiò et al. (2004) found that physical condition was immaterial in the appreciation of quality of life for people with MND. Perceived quality of social support was the most highly associated domain, while psychological and spiritual factors were also explicatory. This supports the argument for the usefulness of a palliative care approach in neurodegenerative diseases, which fundamentally addresses the psychological, interpersonal and spiritual as well as the physical aspects of care (Morrison & Meier, 2004).

The synthesis revealed that not only the effectiveness of interventions was significant but meaningfulness to participants. This corresponds with the existential domain of palliative care. Loss of meaning is particularly relevant for this population. People with neurodegenerative diseases may experience loss of role, everyday activities and future plans which are often perceived to be meaningful. Although meaning cannot be imposed (Chochinov & Breitbart, 2009), healthcare professionals have a potential role facilitating individuals' meaning making.

The importance of trust in healthcare is widely represented in medical literature. Interpersonal trust is considered to be essential in effective healthcare professional-patient relationships and good health outcomes (Brown et al., 2011). At a wider level, Mechanic (1996) asserts that healthcare is one of the most trusted social institutions. Studies have shown that lack of trust in healthcare professionals is associated with non-disclosure of problems and disengaging in care (Priebe, Watts, Chase, & Matanov, 2005); this mirrors the experiences of participants in this metasynthesis. Thom, Hall and Pawlson (2004) suggest that the need for trust stems from the inherent vulnerability of patients due to their illness and lack of expert knowledge. Further, patients want to trust that healthcare professionals are competent and will act in their best interests.

Therapeutic alliance is a useful construct with which to view trust in healthcare relationships. Research has demonstrated that the quality of the alliance is the most robust predictor of successful outcomes in psychotherapy. One of the important aspects of therapeutic alliance is the bond: the connection between the therapist and client. MacEwan (2008) argues that this represents the trust between the two participants in the relationship. This could be translated effectively in non-psychotherapy contexts; healthcare professionals could appraise the therapeutic alliance in end-of-life care, paying particular attention to the bond.

Practice Implications

A palliative care approach would be beneficial to many people with neurodegenerative disease. Timing is important here as some participants reflected that they wished to ‘live in the moment’ and the disease trajectory of many neurodegenerative conditions is long. Therefore, although it is generally beneficial to involve care early, an individualised approach is needed here, with high quality care provided over time at the degree to which it is required. More

widely, this will require a shift in care provision from the more common model of crisis management to a framework of chronic care. This should include anticipating disease milestones and addressing them in a timely way to prevent crises and loss of autonomy. This may take the form of an advance care directive.

Healthcare professionals should support individuals' autonomy and provide adequate information to allow individuals to participate fully in the shared decision-making process. There is a need for information to be individualised. It is well documented that people remember a minority of the information given to them by healthcare professionals (Kessels, 2003). Therefore, repetition and visual memory aids would also be helpful, especially in the context of increasing problems with cognition.

Moreover, healthcare professionals should not only provide information but also the context for discussions, for example, by signalling early on that they are responsible for the patient's end-of-life care needs and encouraging any questions or viewpoints, including around death. Additionally, healthcare professionals should correct any misapprehensions the individual or family might have, such as the idea that advance care directives are only useful for people at terminal stages or that specific care can be demanded. Healthcare professionals should involve families where possible to ensure that the needs of the family as a whole are met but simultaneously ensure that the affected individual's voice is not lost in decision-making processes. This is concordant with European guidelines for integrated palliative care in non-cancer conditions (see Siouta et al., 2016 for a review)

It is noteworthy that the legal status of assisted dying was different in the countries represented in the selected studies. Participants were broadly in favour of assisted dying,

therefore, this study supports the argument for legal provision for assisted dying and should be taken into account in countries where assisted dying is illegal.

Limitations

While every effort was made to search for articles systematically and thoroughly, this is not a comprehensive review. The search strategy chosen relied on database descriptors and subject headings and as a result these limit the scope. Additionally, the selection of studies published in English is a limitation; relevant studies in other languages may exist. However, Doyle (2003) argues that the sample for qualitative review is justifiably purposive, not exhaustive because the aim is interpretation, not prediction.

An inherent issue of metasynthesis is that the findings are twice removed from the actual views and lived experiences of people. The findings are an interpretation of the interpretations of the original researchers.

Finally, although the synthesis found consistency across papers and neurodegenerative diseases share many features, they are heterogeneous conditions. For example, the median life expectancy for MND is 2–5 years after diagnosis (Mitchell & Borasio, 2007) whereas HD is around 20 years (S. A. Simpson, 2007). It is possible that some views on end-of-life care, such as around desire for hastened death, might differ between these populations.

Future research

As qualitative studies considering how stage of disease affects views on end-of-life care and desire for hastened death are limited, future research with people with neurodegenerative diseases could address this gap. Additionally, future research should seek to understand how best to assess the needs of people with neurodegenerative diseases. This is a key prerequisite to creating and implementing care interventions that meet the needs of people with

neurodegenerative diseases. Barriers to implementing a palliative care approach for non-cancer patients should also be identified and guidance put in place to remove them.

Conclusion

This synthesis offers an enhanced understanding of the views of people with neurodegenerative diseases on EOL care by providing theoretically saturated data from the analysis, beyond what would be gleaned from individual studies. This synthesis suggests that the care needs of people with neurodegenerative diseases are routinely not being met, that autonomy and a sense of control are key, that views are contextual and local, and that personality traits (such as the meaning participants make, their beliefs and their preferences for information) shape engagement with care. Personality has been found to be important in many fields of medicine (Wallston, Wallston, & DeVellis, 1978). This is particularly important given that personality changes have been reported in neurodegenerative diseases such as AD and PD.

Also, this synthesis identifies the importance of social context and recommends that care should be individualised and placed in the context of the life of the individual. It clearly advances the case for palliative care for people with neurodegenerative diseases. It is argued here that this should be implemented in a needs-based, integrated way across the disease trajectory as opposed to a traditional, symptom-led approach.

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Tables

Table 1.

Final search terms for each database.

Database	Search terms
Academic Search Complete	(DE "NEURODEGENERATION") OR (DE "HUNTINGTON'S chorea") OR (DE "PARKINSON'S disease") OR (DE "AMYOTROPHIC lateral sclerosis") OR (DE "ALZHEIMER'S disease") OR (DE "MULTIPLE sclerosis-- Treatment") OR (DE "MOTOR neuron diseases") AND (DE "TERMINAL care" OR DE "HOSPICE care" OR DE "PALLIATIVE treatment")
CINAHL	(MM "Neurodegenerative Diseases+") OR (MM "Multiple Sclerosis+") AND (MM "Palliative Care") OR (MM "Terminal Care+") OR (MM "Hospice Care") OR (MM "Hospice and Palliative Nursing")
PubMed	("Neurodegenerative Diseases"[Mesh]) OR "Multiple Sclerosis"[Mesh]) AND ((((("Palliative Care"[Mesh] OR "Hospice and Palliative Care Nursing"[Mesh]) OR "Terminal Care"[Mesh]) OR "Hospice Care"[Mesh]))
PsychInfo	("Neurodegenerative Diseases"[Mesh] OR "Multiple Sclerosis"[Mesh]) AND ((("Palliative Care"[Mesh] OR "Hospice and Palliative Care Nursing"[Mesh]) OR "Terminal Care"[Mesh]) OR "Hospice Care"[Mesh]) AND ("Neurodegenerative Diseases"[Mesh] OR "Multiple Sclerosis"[Mesh]) AND ((("Palliative Care"[Mesh] OR "Hospice and Palliative Care Nursing"[Mesh]) OR "Terminal Care"[Mesh]) OR "Hospice Care"[Mesh])

Table 2.

Articles according to CASP score

Paper	1. Clear statement of aims	2. Qualitative methodology appropriate	3. Appropriate research design	4. Appropriate recruitment strategy	5. Consideration of data	6. Consideration of research	7. Ethical issues considered	8. Rigorous data analysis	9. Findings clearly stated	10. Value of research
Booij (2013)	2	2	1	2	2	1	2	2	2	2
Buchardi (2005)	2	2	1	1	1	1	2	2	2	2
Foley (2014a)	2	2	2	2	1	2	2	1	2	2
Foley (2014b)	2	2	2	2	1	2	2	1	2	2
Galushko (2014)	2	2	2	2	1	0	0	2	2	2
Giles (2009)	2	2	1	2	1	1	2	2	2	2
Greenaway (2015)	2	2	2	2	1	1	2	2	2	2
Hudson (2006)	2	2	2	2	1	2	2	2	2	2
Lemoignan (2010)	2	2	2	2	1	1	2	2	2	2
Poppe (2013)	2	2	1	2	1	1	2	1	1	1
Rosengren (2015)	2	2	1	0	1	1	0	1	2	2
Whitehead (2011)	2	2	2	2	1	2	2	2	2	2
Wollin (2006)	2	2	2	2	1	1	2	2	2	1

Table 3. *Summary information of the studies included in the metasynthesis*

1st Author, Title, Year and Country	Aims	Method	Analysis	(Total) number, gender and age range of participants	Key findings/themes relevant to the review	CASP score
Booij. Euthanasia and advance directives in Huntington's disease: Qualitative analysis of interviews with patients (2013, The Netherlands)	To obtain in-depth information about patients' thoughts on and attitudes to euthanasia, physician-assisted suicide and the use of advance directives in Huntington's Disease	Semi-structured in-depth interviews	Qualitative analysis based on grounded theory	(14) 8 women, 28-70	Background of EOL issues, presence of wishes, knowledge of advance directives, role of family and physician	18
Burchardi. Discussing living wills. A qualitative study of a German sample of neurologists and amyotrophic lateral sclerosis patients (2005, Germany)	To investigate how neurologists provide information about living wills to Amyotrophic Lateral Sclerosis patients. To explore if discussions met patients' needs and expectations.	Semi-structured interviews	Grounded theory techniques	(15), 5 women, 43-78, *M*= 59	Healthcare professional biases, timing of interventions, importance of choice, importance of trust, desire to hasten death, aim to reduce suffering, future decline	16
Foley. Acceptance and decision making in amyotrophic lateral sclerosis from a life-course perspective (2014a, Ireland)	To identify key psychosocial processes that underpin how and why people with Amyotrophic Lateral Sclerosis engage with services.	In-depth interviews	Grounded theory	(34) 17 women, 37-81,	Life and death, acceptance, family context to decision making, views on assisted dying,	18
Foley. Understanding psycho-social processes underpinning engagement with services in motor neurone disease: A qualitative study (2014b, Ireland)	To identify key psychosocial processes that underpin how and why people with motor neurone disease engage with services.	In-depth interviews	Grounded theory	(34) 17 women, 37-81,	Control over care, reassurance from healthcare professionals, importance of trust, meaning of life, meaning of interventions	18
Galushko. Unmet needs of patients feeling severely affected by multiple sclerosis in Germany: A qualitative study (2014, Germany)	To explore the subjectively unmet needs of patients feeling severely affected by multiple sclerosis.	Semi-structured in-depth interviews	Inductive qualitative content analysis	(15) 9 women, 23-73, *M*= 47	Inadequacy of care, family context, trust/lack thereof in healthcare professionals, meaning and identity	15
Giles. Palliative stage Parkinson's disease: patient and family experiences of health-care services (2009, Canada)	To understand the lived healthcare experiences of people with Parkinson's and their families and the needs flowing from these experiences.	Semi-structured in-depth interviews with family groups	Interpretative phenomenological analysis	(2) 2 women, 75-77, *M*= 76	Missing information, being on your own, meaning and identity	17
Greenaway. Accepting or declining non-invasive ventilation or gastronomy in amyotrophic lateral sclerosis: patients' perspectives (2015, United Kingdom)	To identify factors associated with decisions made by patients with amyotrophic lateral sclerosis to accept or decline non-invasive ventilation or gastronomy	Semi-structured interviews	Thematic analysis	(21) 8 women women, 41-76	Perceptions of choice, fear, perceived need and acceptance, influence and support of healthcare professionals, trust,	18

					family context, information needs	
Hudson. Would people with Parkinson's disease benefit from palliative care? (2006, Australia)	To describe the experience of Parkinson's disease and consider the relevance of palliative care for this population	Semi-structured interviews	Thematic analysis	(8) 4 women, 40->80	Contextual factors, emotional impact, staying connected, managing physical challenges, finding help	19
Lemoignan. Amyotrophic lateral sclerosis and assisted ventilation: how patients decide (2010, Canada)	To better understand the experience of decision-making about assisted ventilation for amyotrophic lateral sclerosis patients	Semi-structured interviews	Qualitative phenomenology methodology	(9) 3 women, 36-72	Meaning of intervention, importance of context, importance of values (autonomy), effect of fears, need for information, adaptation and acceptance	18
Poppe. Qualitative evaluation of advanced care planning in early dementia (ACP-ED) (2013, United Kingdom)	To explore the acceptability of discussing advanced care planning with people with memory problems and mild dementia shortly after diagnosis	In-depth interviews	Constant comparison method	(12) 8 women, 68-88, *M*= 79	Information needs, anxiety about future, reassurance from healthcare professionals,	14
Rosengren. Every second counts: Women's experience of living with amyotrophic lateral sclerosis in the end-of-life situations (2015, Sweden)	To describe patients' experiences of living with ALS in the end-of-life situations	Biographies	Manifest content analysis	No demographic information available	Suffering, meaningfulness, unmet care needs, context to decision making	12
Whitehead. Experiences of dying, death and bereavement in motor neurone disease: a qualitative study (2011, United Kingdom)	To explore the experiences of people with motor neurone disease, current and bereaved carers in the final stages of the disease and bereavement period	Narrative interviews	Thematic analysis	(24) 16 women, 25-84	Fears for the future, Information seeking, social and family context, life and death, wishes and decision making, importance of choice, influence of healthcare professionals, euthanasia	19
Wollin. Supportive and palliative care needs identified by multiple sclerosis patients and their families (2006, Australia)	To identify the supportive needs of individuals with multiple sclerosis and their families	In-depth semi-structured interviews	Content analysis	(13) 6 women, 23-55	Lack of support, tracking down services and information,	17

Table 4. *Identified analytical themes and contributing findings and concepts from each study*

Descriptive themes	Analytical themes	Booij (2013)	Buchardi (2005)	Foley (2014a)	Foley (2014b)	Galushko (2014)	Giles (2009)	Greenaway (2015)	Hudson (2006)	Lemoignan (20015)	Poppe (2013)	Rosengren (2015)	Whitehead (2011)	Wollin (2006)
Control and choice Wishes for care Powerlessness and uncertainty Difficult decision making Awareness of decline Interventions can prolong suffering Death and life Personality factors	Importance of autonomy and control	✓	✓	✓	✓			✓	✓	✓	✓		✓	
Lack of information Views on advance care planning Reluctance to talk about end of life Expectations of care Trust/lack thereof in healthcare professionals Bias/neutrality of healthcare professionals	It's the role of HCPs to get the balance of information right (and provide context for discussions)	✓	✓		✓	✓	✓	✓	✓		✓	✓	✓	✓
'Things change' – hope for cure Concept of time Family matters Social comparison Emotions affecting views	Decision making occurs in context	✓	✓	✓		✓		✓	✓	✓	✓	✓	✓	
Inadequate care Illness factors Individualised care needs (emotional, physical, practical support) Promise different to reality Value of specialist services Meaningfulness	Care can't meet all of one's needs		✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

Figures

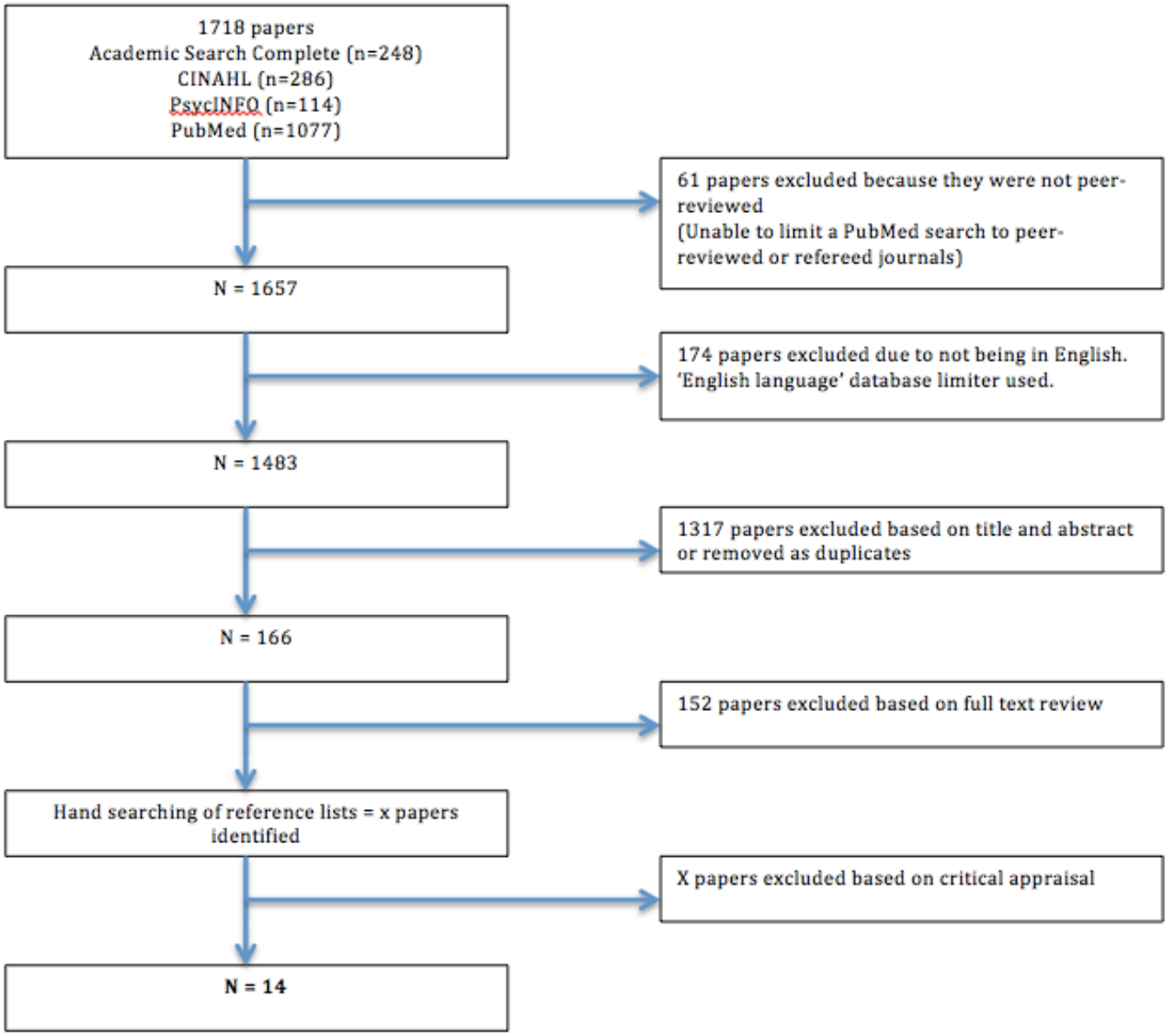

Figure 1. Search process flow chart.

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