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Informational needs of family caregivers of people with intellectual disability who require palliative care: a two phase integrative review of the literature --Manuscript Draft--

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Informational needs of family caregivers of people with intellectual disability who require palliative care: a two phase integrative review of the literature

Short title: Information and palliative caregiving in intellectual disability

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Abstract

People with intellectual disabilities are living longer with increasingly complex needs, their family caregivers may have a broad scope of unmet needs. This two phase literature review utilised five electronic databases (CINAHL, PsycINFO, Medline, Cochrane and Pubmed). Phase 1 involved a review of systematic reviews of the needs of family caregivers across settings. Phase 2 explored the commonly reported 'information needs' from phase 1, in relation to family caregivers of people with intellectual disability who require palliative care. There was no research explicit to the information needs of these family caregivers. The review reveals potential information needs which may exist, guided by the palliative caregiving literature; alluding to information needs surrounding the disease, finances, and psychological or practical support. It is surmised a greater scope of informational need exists for this population and further research is of pertinence at international level.

Background

Age UK (2017) assert that only one in seven people will be free from a long term condition by the time they reach their eighties. Consequently, the number of people providing unpaid care at home to a family member or friend is expeditiously increasing, with recent figures reporting an increase from 16.6% to 17.8% of the population between 2011 and 2015 (University of Essex 2015; Office for National Statistics (ONS) 2016).

Family caregivers are people who provide care for neighbours, relatives or friends who are dependent on them and who do not take payment for these services and they can also be known as informal carers (Thompson and Mathias 2008). These caregivers are now providing exceeding levels of care to people with increased complexity of needs (Age UK 2017).

As the population live longer they are also at increased risk of developing an advanced disease such as Cancer, Dementia, organ failure (including heart failure, end stage respiratory disease, liver failure or renal disease) or degenerative neurological disease, which requires palliative care (Radbruch and Payne 2009; WPCA and WHO 2014). Existing evidence emphasises the needs of family caregivers in palliative care, highlighting the impact of caregiving in relation to the physical, mental, social and financial burden, and the impact of this on their lives and society in general (Payne et al. 2010; Candy et al. 2011).

Initial scoping searches of the literature revealed a paucity of evidence surrounding family caregivers of people with intellectual disabilities who require palliative care. A wider review of systematic reviews was first undertaken to identify all relevant literature in relation to family caregiver needs. Family caregivers of this population may have a broad scope of unmet needs, specifically information needs. A review with specific focus on the information needs of family caregivers of people with intellectual disabilities who require palliative care was then undertaken.

Rationale for a two phase review

Two phases were undertaken to cover the vast array of literature in relation to the needs of family caregivers in general, and to hone in on the specific information needs of family caregivers of people with intellectual disabilities in palliative care.

A review of systematic reviews of the needs of family caregivers was conducted for phase 1. Phase 2 further explored the commonly reported 'information needs' from the broader literature in phase 1, and applied this to family caregivers of people with intellectual disabilities who require palliative care.

Overall Aims

To identify the most common needs of family caregivers; to highlight gaps in the literature and distinguish the 'information needs' of family caregivers of people with intellectual disabilities who require palliative care.

Phase 1 review of systematic reviews objectives were:

- To examine general 'needs' of family caregivers providing care to adults, from palliative care extending to those providing longer term care in chronic illness or intellectual disability.
- To reveal commonly cited needs.
- To identify under-researched subgroups of family caregivers.

Phase 2 literature review, adjunct to and informed by phase 1 in order to:

- Identify published research around the information needs of family caregivers of people with intellectual disabilities who require palliative care.

Methods

Phase 1 follows guidelines for systematic conduct and reporting, in line with Aveyard's (2014) systematic approach and PRISMA reporting (Moher et al. 2014).

Search Strategy

Both phases involved inspection of five electronic databases (CINAHL, PsycINFO, Medline, Cochrane and Pubmed).

Phase 1 Keywords:

Family care* (* to include carers and caregivers) OR **Informal care***
(* to include carers and caregivers) AND **Needs AND Systematic Review.**

Inclusion: Informal or family caregivers of adults over the age of 18. Systematic Reviews or systematically conducted integrative reviews, as these are considered a subset of systematic reviews (Gunnarsson 2014). There were no restrictions applied on date or language.

Exclusion: Papers that did not meet the search criteria. Reviews that involved formal or paid caregivers, or caring for children rather than adults. Narrative and literature reviews.

There was a further hand search of pertinent journals and reference lists from seminal papers. Abstracts meeting initial criteria were screened and selected for full text retrieval based on relevance.

Selection and Quality Appraisal: Papers falling outside of the inclusion or exclusion criteria were rejected. Irrelevant or duplicate papers were also dismissed. Each review was critically appraised using the 10 question CASP (2018) systematic review checklist tool (www.casp-uk.net).

Phase 1 Results

Whilst there were many literature reviews and primary studies, a total of 16 systematic reviews were identified concerning the needs of family caregivers (figure 1).

Figure 1

Extraction of the data

Systematic reviews revealed an international demographic spread: UK= 4, Australia= 3, Canada= 3, United States (US) = 2, Spain= 1, Portugal= 1, France= 1 and the Netherlands= 1. Key characteristics of each review are presented in the data extraction table (Table 1).

Results

Family caregiving populations across specialties

Four systematic reviews (Innes et al. 2011; Afram et al. 2015; McCabe et al. 2016; Novais et al. 2017) and one protocol for systematic review (González-Fraile et al. 2015) were concerning family caregivers of people with Dementia. Three considered caregiving in palliative and end of life care (Docherty et al. 2008; Cagle et al. 2017; Rainsford et al. 2017).

Two reviews were specific to Cancer caregiving (Bee et al. 2009; Wheelright et al. 2015), and Lunskey et al. (2014) and Balogh et al. (2008, 2016) explored caregiving in intellectual disability. One review focused on post Stroke care (Forster et al. 2012), another, chronic health conditions (Washington et al. 2011), and a further review considered caring for elderly (Silva et al. 2013).

Commonly identified need for Information

Analysis identified a running theme of information need/information provision for family caregivers. Information regarding available services, access to services and support, information on self-care, and information and signposting to psychosocial support were deemed important for family caregivers. Information was a common need and priority for family caregivers across caregiving populations. Moreover, a specific information need was surrounding the disease, its trajectory, and practical management.

Beaver and Witham (2007) suggest that the term 'information need' entails the recognition and assertion of poor provision or receipt of information. Sources agree that information has a recognised impact on how well a caregiver copes with the stress and burden associated with their role, including how information is delivered and by whom (Rose, 1999; Bee et al. 2009; Washington et al. 2011; Lunskey et al. 2014; Afram et al. 2015).

McCabe et al. (2016) concur with their predecessors Parker et al. (2007), Docherty et al. (2008) and Bee et al. (2009) and Afram et al. (2015) in recognising information as an important facilitator of services, support, and knowledge, to promote and enable caregiver competency. There is consensus that information is individualised depending on each family caregiver (Forster et al. 2012; Silva et al. 2013; Lunskey et al. 2014; Afram et al. 2015).

Tailored information aids choice (Eysenbach 2000) and can facilitate holistic support inclusive of respite, education and training, financial assistance, and psychosocial support (DH 2008a; Philip et al. 2014). Across all settings information was seen as preparatory and a priority for health care providers.

Recommendations called for the provision of tailored information (Docherty et al. 2008; Washington et al. 2011, Lunksy et al. 2014; Afram et al. 2015). Balogh et al. (2008; 2016) also recommended specialised integrated support in the community to foster a more organised system of services and support provisions.

Findings across settings traverse due to some overlap of specialities and illnesses. Most reviews concerned Dementia/Alzheimer's (5) and palliative and end of life care, including end of life care in Cancer (4). Importantly, the WPCA and WHO (2014) categorise Dementia as a progressive disease, which may require palliative care in the advanced stages. Furthermore, Dementia is a co-morbid disease frequently associated with the ageing population of people with Down Syndrome (Towers and Glover 2015). Palliative care may also be prescribed for patients following acute stroke (Singh et al. 2017).

Discussion

In seeking to scope the individualised needs of each population of caregivers including: those caring for people with dementia, cancer, intellectual disability, stroke, chronic health conditions, and for those who were elderly or required palliative care, there was moderate homogeneity of findings. 'Information needs' were most frequently reported. Furthermore, reviews reported other needs defined as psychological need, respite requirements, education on the illness, practical support, and financial assistance. All of which may be considered areas of information need. Some caregiving populations were under researched in relation to others, for example, the abundance of literature surrounding dementia, and palliative care, in comparison to intellectual disability or elderly stroke.

Limitations

Despite the breadth of insight and knowledge gained, limitations were identified through the CASP (2018) appraisal tool for systematic reviews. Structured quality assessment was not explicitly reported by Innes et al. (2011), Washington et al. (2011), Lunskey et al. (2014), Novais et al. (2017) and Cagle et al. (2017). Some reviews were limited by date (Innes et al. 2011; McCabe et al. 2016; Balogh et al. 2016; Rainsford et al. 2017), whilst others included published works only (Parker et al. 2007; Docherty et al. 2008; Innes et al. 2011; McCabe et al. 2016; Rainsford et al. 2017).

A restriction on inclusion criteria may have excluded valuable evidence and limits generalisability of findings to similar populations. However, findings are valuable nonetheless due the systematic nature of the reviews

Phase 1 Conclusion

There were similarities in unmet needs identified, as well as corroborating evidence of the need for information. This phase also highlights family caregivers of people with intellectual disabilities as one of the comparatively under-researched groups. This is significant due to an increasing population of people with intellectual disabilities living into older age, with co-morbid conditions or advanced illnesses requiring palliative care. Crucially, the long term family caregivers of this population may be hidden to services, with their needs unknown (McLaughlin et al, 2014a; Tuffrey-Wijne et al. 2016).

The importance of identifying information needs of family caregivers of people with intellectual disabilities is strengthened by the recent population statistics. Figures suggest that long term family caregivers of people with intellectual disabilities may be faced with problems similar to caregiving in dementia, palliative care, Cancer, stroke or chronic illness, as the person they care for grows older (Kirkendall et al. 2012; Tuffrey-Wijne et al. 2016; Age UK 2017).

Phase 1 demonstrates ‘information needs’ are common. Information is an important facilitator in supporting family caregivers. Applying this knowledge around information need to family caregivers of people with intellectual disabilities who require palliative care sheds light on which information needs may exist for these under researched family caregivers. Phase 2 seeks to examine the specific information needs of family caregivers of people with intellectual disabilities who require palliative care.

Phase 2 Background

It is reported within the United Kingdom (UK) that Health and Social Care professionals have historically demonstrated insufficient knowledge, training or awareness of intellectual disability (Mencap 2007; Michael 2008; Heslop et al. 2013; Parliamentary and Health Service Ombudsman (PHSO) 2009, 2014). As a result, recommendations for 'reasonable adjustments' to care and support have been made in relation to the provision of meaningful care for people with intellectual disabilities and their caregivers, as vulnerable groups (PHSO 2009).

It is important to acknowledge that a late diagnosis for a palliative illness can occur in people with intellectual disability, due to lack of screening, or diagnostic overshadowing; the latter term is given where people may attribute symptoms or changes in behaviour to the intellectual disability, as opposed to an advanced co-morbid disease (Reiss et al. 1982; Heslop et al. 2013; Tuffrey-Wijne et al. 2016).

UK reports "Equal Lives" (DHSSPS 2005), "Healthcare for All" (Michael 2008), "Six Lives" (PHSO 2009), the "Confidential Inquiry into premature deaths of people with intellectual disabilities (CIPOLD)" (Heslop et al. 2013), "Dying without dignity" (PHSO 2014) and the more recent EAPC White Paper (Tuffrey-Wijne et al. 2016) have highlighted historical discrimination and access inequalities that have existed in the healthcare system for people with intellectual disabilities.

Frequently cited issues around access to information and service provisions have a profound impact upon family caregivers. 'Living Matters, Dying Matters' (DHSSPS 2010) acknowledged the contribution of family caregivers in palliative care. It recognised the prevalence of chronic conditions, and the similar burden of symptoms to that of a malignant condition. Olson (2008) approached the importance of advance care planning and of family members as translators, who can interpret behaviours and language. Tuffrey-Wijne and McLaughlin (2015) more recently provided consensus norms and standards for the provision of palliative care for people with intellectual disability, reflected in their EAPC White Paper (Tuffrey-Wijne et al. 2016).

European level policy and recommendations attempt to reduce pockets of marginalisation and assumptions, promoting the involvement and support of family caregivers in palliative care and intellectual disability (DH 2008a, 2008b; Radbruch and Payne 2010; Tuffrey-Wijne et al. 2016). However, services remain fragmented and difficult to access (McLaughlin et al. 2014b; Tuffrey-Wijne et al. 2016). This extends internationally (Kirkendall et al. 2012; Balogh et al. 2016).

Phase 2 keywords:

Family care* OR Informal care*

AND

Intellectual disabilit* OR Learning Disabilit* OR Developmental disabilit*

AND

OR Information OR Information needs

AND

Palliative care OR End of life OR Hospice

Inclusion: Published papers. Informal or family caregivers. Caregivers of adults over the age of 18. No date restrictions.

Exclusion: Papers that did not meet the search criteria. Papers that involved formal caregivers, or caring for children.

Additional records identified were retrieved from hand searches of reference lists.

Selection and Quality Appraisal: Papers were assessed for quality and scored using the relevant CASP (2018) checklist (www.casp-uk.net). Poor quality, irrelevant or duplicate papers were dismissed (figure 2).

Figure 2

Phase 2 Results

8 published papers were identified for review. These papers are discussed alongside and in context to other relevant literature, government policies, and inquiry reports. Article demography revealed studies had taken place across a variety of countries, but were weighted within the UK: UK= 5, United States (US) = 1, New Zealand = 1 and the Netherlands = 1. Details of the selected papers are provided in the data extraction table (Table 2).

Connecting Services and Partnership Working

Tuffrey-Wijne et al. (2007a) explored palliative care for people with intellectual disabilities and reported issues around diagnostic disclosures, presentation of symptoms, late diagnoses, poor communication, and ethical issues around decision making. Collaboration between intellectual disability and palliative care services and partnership work with family caregivers were highlighted. Training needs identified included carer information needs on the disease, and how to access palliative care services. Service planning, end of life decision making, and recognition of the psychosocial issues experienced by the person with intellectual disability and their family caregivers were also featured (Tuffrey-Wijne et al. 2007a).

Similar issues surrounded the role of paid staff (n=32) in the provision of palliative care for people with intellectual disabilities (Tuffrey-Wijne et al. 2007b). Study findings support other intellectual disability literature (Tuffrey-Wijne et al. 2007a; Lunskey et al. 2014; Balogh et al. 2016) in promoting identification of: family issues, assessment problems, emotional fears, and considering the effectiveness of good communication between staff, patient and carers. Tuffrey-Wijne et al. (2007b) recommended staff are trained in intellectual disability, and the expertise of the family caregivers recognised.

McLaughlin et al. (2014b) identified positive partnership working between intellectual disability and palliative care services, however, referrals to specialist palliative care were limited. The mixed methods study incorporated Health and Social Care professionals (n=30) from both fields. Learning needs concurred with Tuffrey-Wijne et al. (2007a, 2007b) suggesting staff require better understanding of intellectual disability, supporting the carer, and coping with the aftermath of a diagnosis and/or death. A best practice model for partnership working was proposed, with development of improved training for professionals (McLaughlin et al. 2014b).

Similarly concerning integration of services, Kirkendall et al. (2012) evaluated care for people with intellectual disability and life limiting illness, and recognised people with intellectual disabilities were living longer with little known about their end of life needs. In the United States, Kirkendall et al. (2012) acknowledged partnerships between intellectual disability services and palliative services were on the increase, yet the effectiveness of such was under researched. The authors argued that managing the care of someone with intellectual disability in the community employed divergent ideologies of care to palliative and end of life care services. Authors' further postulate that a disparity between fields and approaches creates issues for both disciplines and suggested partnership working and collaborative practice to promote information sharing and shared awareness.

In the Netherlands, Bekkema et al. (2015) also highlighted the importance of enhanced therapeutic relationships between the informal and paid carers. Study participants (n=45) included family and Health and Social Care professionals who were involved with someone with intellectual disability at end of life. Important values identified were being responsive and reflective, and taking responsibility in cooperating in shared care. Family carers required support from professionals to make difficult decisions and teamwork was championed (Bekkema et al. 2015).

Accessibility and Equity of Information and Services

McLaughlin et al. (2014b) attested to a gap in services and lack of accessibility for people with intellectual disability to quality end of life care. Recommendations were for services to be intertwined enabling access to the right services and information, for someone to die in their place of choice, and for continuity of care delivered by those familiar to them.

24 hour ongoing information and support for family caregivers of someone with intellectual disability who required end of life care was also valued and recommended in a small qualitative study (n=5) conducted by Marlow and Martin (2008) in New Zealand. The study advocated sensitive communication between professionals and caregivers to facilitate this.

In relation to the education of professionals in palliative care and the support of people with intellectual disabilities, McLaughlin et al. (2014a) explored the perspectives of service users. Findings from focus groups (n=17) and semi structured interviews (n=5) revealed key themes involving partnership, shared learning, support and empowerment, and issues and challenges at end of life. This study suggested early referrals to promote adequate information provision in a timely fashion, and the formation of trusting relationships. Late referrals remained an apparent barrier, however, to collaboration, information provision, and signposting to supportive interventions.

More recently, Tuffrey-Wijne et al. (2016: 452-453) conducted a European Delphi study to assist drafting of norms for people with intellectual disabilities requiring palliative care. Norms included 'communication; equity of access; recognising the need for palliative care; assessment of total needs; end of life decision making, symptom management, involving those who matter; support for family and carers; collaboration; preparing for death; bereavement support; education and training, and developing and managing services.'

Tuffrey-Wijne et al. (2016) concluded a lack of data on people with intellectual disability who require palliative care. Recommendations included sharing of best practice, involvement of family caregivers, and modifications in policy in order for change. The recent White Paper (Tuffrey-Wijne and McLaughlin 2015, p54) suggests that palliative care services actively reach out to uncover this 'hidden' population in order to assess their needs, deliver support, and encourage carers' involvement as 'expert care partners.'

Discussion

Family caregiving research in the intellectual disability field is limited in comparison to palliative caregiving, and there were no studies identified specific to the information needs of family caregivers of people with intellectual disabilities who require palliative care.

Tuffrey-Wijne et al. (2007a) focused on the person with a disability as opposed to the family caregiver and Tuffrey-Wijne et al.'s (2007b) primary study explored only the role of paid staff, as did the Bekkema et al. (2015) study. However, both papers provide insight and knowledge into the role of family caregivers and importance of paid staff supporting family caregivers in meeting potential information and support needs.

Some research concerned small numbers of participants (Marlow and Martin 2012; McLaughlin et al. 2014a), however due to the exploratory qualitative designs, findings provided rich information also important to understanding the potential information needs of family caregivers of people with intellectual disabilities who require palliative care. In particular, Marlow and Martin (2008) offer a window into the world of a family caregiver of someone with intellectual disability who is dying; however, further exploratory work with a larger sample is warranted.

Tuffrey-Wijne et al. (2016) support Kirkendall et al.'s (2012) assertion that if each field identifies the other's similar philosophy of care then there will be intermutual harmony, which will benefit family caregivers in addressing their needs. Within the UK, the philosophy of a 'good death' (DH 2010b) in palliative care is similar to the philosophy of living a 'good life' within the intellectual disability field (BILD 2015). These congruent philosophies promote the benefits of joint working for people with intellectual disabilities who require palliative care, and their family caregivers (Kirkendall et al. 2012; McLaughlin et al. 2014a).

Kirkendall et al. (2012) and McLaughlin et al. (2014a) both promote adequate information provision through good communication and partnership working across fields.

Limitations

The majority of literature was UK based which may not be a reflection of the status of the needs of family caregivers in other countries, due to the nature of how government systems and health care services are organised elsewhere. There was no reporting of quality of material reviewed in the Tuffrey-Wijne et al. (2007a) paper, dates were also limited from 1995-2005 meaning useful material may have been overlooked. However, as there was such little research at the interface of intellectual disability and palliative care services at that time, the evidence remains advantageous.

Phase 2 Conclusion

This review highlights the gap in the research in relation to the specific informational needs of family caregivers of people with intellectual disabilities who require palliative care. It sheds light however on what informational needs may exist based on the evidence retrieved. The scope of information required may be extensive and dependent on the individual caregiver at the interface of intellectual disability and palliative care services, taking into account the existing and lengthy care trajectory associated with caring for someone with intellectual disability, prior to a palliative diagnosis.

Implications for Practice and Future Research

A palliative diagnosis may compound any existing carer burden associated with the complex care of someone with an intellectual disability (Kirkendall et al. 2012). Supporting populations of family caregivers, such as those providing care to people with intellectual disabilities who require palliative care, by identifying and addressing their informational needs, fosters improved quality of life and meaningful fiscal and societal contribution.

Overall conclusions

There is a wide body of international literature concerning palliative caregiving in comparison to family caregivers of people with intellectual disabilities, in general. 'Information needs' were most commonly identified with other caregiving populations across specialities, including disease specific information, practical information and financial information.

We also know that access to information and equity of available services remain barriers to meeting the information needs of family caregivers comprehensively, across settings in various countries. We do not however know the specific information needs of family caregivers of people with intellectual disabilities who require palliative care, highlighted by the gap in the literature in phase 2.

Crucially, the needs of people with intellectual disabilities who require palliative care, and their family caregivers, are of importance at European level and a policy direction priority (Tuffrey-Wijne et al. 2016). Internationally, this cohort of family caregivers may be hidden to services; it is therefore important that further research is conducted to ascertain if similar information needs exist, and how they can be addressed.

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Figure 1

Figure 2

Table 1

Author(s)/Year	Country/Setting	Aims & Objectives	Number of studies included	Population of caregivers concerned	Outcome/Findings
Docherty et al. (2008)	United Kingdom	A systematic review	34 studies	Informal caregivers in	Inadequacies highlighted in
		considering the knowledge		Palliative care	relation to knowledge and
		and information needs			education, in particular
		of informal caregivers in			around pain management.
		palliative settings			Weaker evidence of
					knowledge and information
					needs in relation to welfare
					and social support. Effective
					communication significant in
					information sharing
Bee et al. (2009)	United Kingdom	A systematic review	26 studies	Informal caregivers of people	A general lack of practical
		examining practical		in receipt of palliative and	support related often times to
		information needs of informal		end of life care for advanced	inadequate information
		caregivers who provide		cancer	provision or exchange.
		home-based palliative and			Family members as a result
		end-of-life care to people with			adopt a 'trial and error'
		advanced stage cancer			approach, despite needing a
					wide scope practical-focused
					information

Innes et al. (2011)	Canada	A systematic review to evaluate existing evidence surrounding informal/family caregiving in remote or rural settings to ascertain state of caregiver knowledge	26 studies	Informal/family caregivers of people with Dementia living rurally or remotely	Four themes: Service use, carer experience, rural perceptions of dementia, and support and education
Washington et al. (2011)	United States	A systematic examination of the information needs of informal caregivers of older adults with chronic conditions	62 articles	Informal caregivers of older people with chronic illness	Lack of education and information in general: disease specific information, treatment options, and information around services. Two kinds of information need: general factual information, explanations and advice; specific individualised information
Forster et al. (2012)	United Kingdom	Cochrane systematic review on information provision for stroke patients and their caregivers	21 Randomised Control Trials	Family caregivers of someone who had suffered a stroke	9 trials= passive information intervention, 12= active information intervention. Information had a significant effect on caregiver knowledge (P= 0.03). No significant effect on carer satisfaction or mood. Sufficient information provision following discharge back to the home setting

Silva et al. (2013)	Portugal	To review the needs of informal caregivers providing care to people who are elderly (integrative)	14 articles	Informal caregivers providing care to elderly people in the home setting	Four core themes: professional support, legal and financial support, effective communication, and information and training
Lunsky et al. (2014)	Canada	Systematic scoping review of the literature surrounding family carers of people with intellectual/developmental disabilities	87 papers	Family carers of someone with intellectual or learning disability	Authors reported carer burden, depression, and stress. The need for respite care and information on available services for family caregivers. Financial planning, future planning, and awareness of financial entitlements were distinguished needs
Afram et al. (2015)	The Netherlands	A systematic review on the needs of informal caregivers of people with Dementia during transition from home to institutional care	13 publications	Informal carers of people with Dementia	14 topics of 'need' from the literature, with the most prominent topics including 'knowledge and information', 'emotional concerns' and 'support.'

Gonzalez-Fraile et al. (2015)	Spain	Cochrane systematic review on information, support and training of those caring informally for people with Dementia [protocol]	N/a protocol only	Informal caregivers of people with Dementia	Information was one of three priority areas identified by the authors, which supports other evidence and reflects the current status of caregiver information needs. Authors argue information needs of family/informal caregivers should be a priority for future research
Wheelright et al. (2015)	United Kingdom	A systematic review on quality of life of informal carers of patients with cancer cachexia	16 studies	Informal carers of people with cancer cachexia	Five key themes: impact on everyday life, the need for healthcare professionals' input, conflict with patient/negative emotions, and attempts of some carers to take charge. Acknowledgement of carer burden and importance of provision of education around cachexia

Balogh et al. (2009; 2016)	Canada	Cochrane review (updated) of how healthcare systems are organised for people with an intellectual disability and their caregivers	2009: 8 studies 2016: 7 studies (6 already included in 2009 review)	Family caregivers/relatives of someone with an intellectual or learning disability	In relation to the family caregivers, caregiver burden and financial costs of providing care were acknowledged. Extended care into the community is recommended, with integrated care teams, to support the person and their family caregiver
McCabe et al. (2016)	United States	A systematic review of the needs of family caregivers of people with Dementia	12 Studies	Family caregivers of people with Dementia	Two main themes: caregivers' personal needs and caregiver needs related to the management of older people with Dementia. Subthemes included: information and knowledge needs, caregivers' own needs, and addressing caregivers' physical and psychological needs

Cagle et al. (2017)	United States	Systematic review examining the psychosocial needs and interventions specific to families and patients receiving palliative care for Heart Failure	17 articles	Family caregivers of people receiving palliative care for Heart Failure	Provision of information relating to the disease, symptoms, pain management deemed important. Poor provision of information = emotional distress. Educating via information suggested to reduce distress and caregiver burden
Novais et al. (2017)	France	A systematic review of the methodologies used to identify the needs, instruments of needs assessment and the general topic of needs of caregivers of people with cognitive impairment in Alzheimer's or related diseases	70 studies	Informal caregivers of people with cognitive impairment in Alzheimer's disease, or related diseases	Top topic of needs explored within instruments was 'information needs'; on the disease, medications, treatment options and available services. Psychological and psychoeducational needs were rated, however information needs were particularly important

Parker et al. (2017)	Australia	A systematic review of patient/caregiver preferences for information around prognostic or end of life communication at the end stage of a person's illness	123 articles	Family caregivers of people at the end of life stage of illness	Information needs concerning stage of disease, symptom management, and treatment options. Information following a diagnosis was key, alongside its delivered and by whom. Content and scope of information need was negotiated depending on the individual caregiver
Rainsford et al. (2017)	Australia	A systematic literature review on rural end of life care from the perspective of family caregivers and patients	27 articles	Family caregivers of people receiving palliative and end of life care within rural areas	Increased responsibility with the need for coordinating and advocating for the person at end of life. Many caregivers were unprepared physically, emotionally and educationally. Accurate information was the main identified need along with medication needs

Table 2

Author(s)/Year	Country/Setting	Aim	Design and Sample	Data Collection	Data Analysis	Outcome/Findings
Tuffrey-Wijne et al. (2007a)	United Kingdom	A review of the literature on palliative care and end of life care for people with intellectual disabilities	Literature review of 45 sources	Not applicable	Not applicable	Issues reported: prognostic disclosures and presentation of symptoms, late diagnoses, and poor communication. Training and information needs of family carers identified as well as access to palliative care services. Importance of service planning
Tuffrey-Wijne et al. (2007b)	United Kingdom: Specialist Palliative Care Services	An investigative study into the issues and difficulties experienced by palliative care staff in relation to the provision of palliative care for people with intellectual disabilities	Qualitative: 32 palliative care professionals	Semi-structured interviews	Thematic Analysis	Identification of: family issues, assessment problems, emotional fears, and the effectiveness of good communication between staff, patient and carers, were promoted

Marlow and Martin (2008)	New Zealand: Community	To provide understanding of inner meanings of the experience of supporting a dying family member with an intellectual or learning disability	Qualitative Hermeneutic Heideggerian phenomenological : 5 family caregivers	Semi-structured interviews	Hermeneutic Phenomenological	Themes - (1) interlocked companionship (2) Search for new balance (3) permeable interaction
Kirkdendall et al. (2012)	United States	Peer reviewed article on caring for people with intellectual or learning disabilities and life limiting illness	Review	Not applicable	Not applicable	Intellectual/learning Disability and Palliative care services need to build relationships, share goals and merge philosophies to be successful
McLaughlin et al. (2014a)	United Kingdom: advocacy network and community	To explore service user perspectives on palliative care education for health and social care professionals supporting people with intellectual/learning disabilities	Qualitative exploratory: 17 people with intellectual/learning disabilities and 5 family caregivers	Focus groups and semi-structured interviews	Qualitative content analysis	Themes - (1) Partnership between practices (2) shared learning (3) support and empowerment and (4) challenges at end of life

McLaughlin et al. (2014b)	United Kingdom: primary and secondary care settings (specialist palliative care and intellectual/learning disability services)	Developing a best practice model for partnership practice between specialist palliative care and intellectual/learning disability services	Mixed Methods: 66 services (phase 1) and 30 health and social care professionals (phase 2)	Questionnaires (phase 1) and semi-structured interviews (phase 2)	SPSS to obtain descriptive statistics (phase 1) and Qualitative content analysis (phase 2)	Positive partnership working, however referrals for palliative services were limited. Better understanding of intellectual/learning disability required with supporting the carer coping with the aftermath of a palliative diagnosis and death
Bekkema et al. (2015)	Netherlands: community intellectual/learning disability intensive care unit, hospital and hospice	To explore the perspectives of relatives, care staff and physicians on shifts in care approaches at the end of life of people with intellectual/learning disabilities	Qualitative retrospective care study: 45 relatives and healthcare professionals	Semi-structured interviews	Inductive thematic analysis	End of life care for people with intellectual/learning disability requires increased teamwork and fostering of collaborative relationships among professionals and relatives. Joint decision making, cooperation and shared care in the best interests of the person

Tuffrey-Wijne et al. (2016)	United Kingdom: involving experts from 15 European countries	To define consensus norms for palliative care of people with intellectual/learning disabilities in Europe	Mixed Methods Delphi study composed of four rounds	(1) taskforce drafting of norms (2) Online survey to evaluate norms (3) modification and recommendations from taskforce (4) Review and approval from the European Association for Palliative Care	Statistical analysis for quantitative components	Norms were inclusive of equity of access to palliative care services; recognition of palliative care need; needs assessment; involving important people; support for family carers; preparation for death and support in bereavement; and education and training
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