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


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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.
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](http://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

Records identified through database searching (n = 521)

Additional records identified through other sources (n = 1)

Records screened after duplicates removed (n = 507)

Records excluded (n = 484)

Full text articles assessed for eligibility (n = 23)

Full-text articles excluded (n = 6)

Systematic Review Papers (n = 15)
Protocol for Systematic Review (n = 1)

Identification

Screening

Eligibility

Included

CINAHL (41)
PsycInfo (40)
Medline (76)
Pubmed (358)
Cochrane (6)
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 Lunsky 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; Lunsky 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; Lunsky 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), Lunsky 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 to 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

Identification

All search terms
- CINAHL (9)
- PsycInfo (14)
- Pubmed (20)
- Cochrane (1)
- Medline (64)

Additional records identified through other sources (n = 2)

Records identified through database searching (n = 108)

Screening

Records screened after duplicates removed (n = 105) + (n = 2)

Eligibility

Full text articles assessed for eligibility (n = 8)

Included

Papers included in review (n = 8)

Qualitative (4)
Mixed Methods (2)
Review (2)

Records excluded= (n = 99)
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; Lunsky 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.

References


Bee PE, Barnes P, Luker KA (2009) A systematic review of informal caregivers’ needs in providing home-based end-of-life care to people


(DH) Department of Health (2008b) End of Life Care Strategy:
Promoting high quality care for all adults at the end of life.


disabilities (CIPOLD). [https://rcpsych.ac.uk/pdf/Confidential Inquiry into premature deaths full report.pdf](https://rcpsych.ac.uk/pdf/Confidential Inquiry into premature deaths full report.pdf) (accessed 27 June 2018)


(PHSO) Parliamentary and Health Service Ombudsman (2009) Six lives: the provision of public services to people with learning disabilities Part one: overview and summary investigation reports


(accessed 18 June 2018)
Figure 1

Identification

Records identified through database searching (n = 521)
- CINAHL (41)
- PsycInfo (40)
- Medline (76)
- Pubmed (358)
- Cochrane (6)

Records screened after duplicates removed (n = 507)

Records excluded (n = 484)

Eligibility

Full text articles assessed for eligibility (n = 23)

Full-text articles excluded (n = 6)

Included

Systematic Review Papers (n = 15)
- Protocol for Systematic Review (n=1)
Figure 2

Identification:

- **All search terms**
  - CINAHL (9)
  - PsycInfo (14)
  - Pubmed (20)
  - Cochrane (1)
  - Medline (64)

Records identified through database searching (n=108)

Screening:

Records screened after duplicates removed (n=105) + (n=2)

Eligibility:

Full text articles assessed for eligibility (n=8)

Included:

- Papers included in review (n=8)
  - Qualitative (4)
  - Mixed Methods (2)
  - Review (2)

Records excluded= (n = 99)

Additional records identified through other sources (n = 2)
<table>
<thead>
<tr>
<th>Author(s)/Year</th>
<th>Country/Setting</th>
<th>Aims &amp; Objectives</th>
<th>Number of studies included</th>
<th>Population of caregivers concerned</th>
<th>Outcome/Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Docherty et al. (2008)</td>
<td>United Kingdom</td>
<td>A systematic review considering the knowledge and information needs of informal caregivers in palliative settings</td>
<td>34 studies</td>
<td>Informal caregivers of people in receipt of palliative care</td>
<td>Inadequacies highlighted in relation to knowledge and education, in particular around pain management. Weaker evidence of palliative care.</td>
</tr>
<tr>
<td>Bee et al. (2009)</td>
<td>United Kingdom</td>
<td>A systematic review examining practical information needs of informal caregivers who provide home-based palliative and end-of-life care to people with advanced stage cancer</td>
<td>26 studies</td>
<td>Informal caregivers of people in receipt of palliative and end-of-life care for advanced cancer</td>
<td>A general lack of practical information sharing. Family members as a result adopt a ‘trial and error’ approach, despite needing adequate support related often times to inadequate information provision or exchange.</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Aim</td>
<td>Methodology</td>
<td>Findings</td>
<td></td>
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<tr>
<td>Innes et al. (2011)</td>
<td>Canada</td>
<td>A systematic review to evaluate existing evidence surrounding informal/family caregiving in remote or rural settings to ascertain state of caregiver knowledge</td>
<td>26 studies</td>
<td>Four themes: Service use, Knowledge, Experience, and Support and Education</td>
<td></td>
</tr>
<tr>
<td>Washington et al. (2011)</td>
<td>United States</td>
<td>A systematic examination of the information needs of informal caregivers of older adults with chronic conditions</td>
<td>62 articles</td>
<td>Two kinds of information need: general factual information, explanations and advice; specific individualized information needs</td>
<td>Informal caregivers of older adults with chronic conditions need detailed information on chronic conditions, care options, people with chronic illness, and lack of education and formal caregivers of older adults.</td>
</tr>
<tr>
<td>Forster et al. (2012)</td>
<td>United Kingdom</td>
<td>A Cochrane systematic review on information provision for stroke patients and their caregivers</td>
<td>21 Randomised Trials, 9 passive information intervention, 12 active intervention</td>
<td>Family caregivers of someone who had suffered a stroke</td>
<td>Information had a significant effect on caregiver knowledge (P=0.03). No significant effect on caregivers' satisfaction or mood. Sufficient information provision following discharge back to the home setting.</td>
</tr>
</tbody>
</table>
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, information on available services, 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 an institutional care setting
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.'
Informal caregivers of people with Dementia

Information was one of three priority themes identified in informal caregivers of people with Dementia. Authors argue that information needs of family/informal caregivers should be a priority for future research.

- Provision of education and information around the condition and importance of care
- Care management and future implications

Informal caregivers often need support and education to navigate this role. There is a need for more research on the support needs of informal caregivers and the importance of educational and information needs.

Wheelwright et al. (2015) - United Kingdom

A systematic review on the quality of life of informal caregivers of people with cancer cachexia

16 studies

- 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 the condition and importance of care are important areas for future research.
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 people with disabilities

Extended care into the community is recommended, with integrated care teams, to support the person and their caregiver.

McCabe et al. (2016)
United States
A systematic review of the needs of family caregivers of people with Dementia

- 12 studies

Two main themes:

- Emotional needs of family caregivers of people with Dementia
- Financial needs of people with an intellectual disability and their caregiver

Subthemes included:

- Information and knowledge needs
- Caregivers' own needs
- Addressing caregivers' physical and psychological needs

Supporting the person and their caregiver.

Informed care teams, to address the needs of the community, are expanded.

Providing care where needed, for people with an intellectual disability, and their families.

Caregivers are acknowledged and included in 2009 review.

Caregivers' needs and financial costs of caregivers are managed, with integrated care teams, to support the person and their family caregiver.
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

Individual 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 caregivers 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. 70 studies

Informal caregivers of people with cognitive impairment in Alzheimer’s disease, or related diseases
Top topic of needs explored was information needs; on the disease, medications, treatment options and available services. Psychological and psychoeducational needs were rated, however information needs were rated highest. In Alzheimer’s disease care, emotional distress, caregivers’ distress, and communication issues were high. Familiarization with palliative care and receiving palliative care for relatives were also mentioned.

Cadle et al. (2017) United States
Systematic review examining the psychosocial needs 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 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's needs and goals of care. Many caregivers were unprepared physically, emotionally and mentally. The need for coordinating and controlling palliative care was key. The perspective of family caregivers was increased responsibility within the care team and rural areas. Accurate information was the main need along with medication needs

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 controlling care. Many caregivers were unprepared physically, emotionally and educationally. Accurate information was the main need along with medication needs
<table>
<thead>
<tr>
<th>Author(s)/Year</th>
<th>Country/Setting</th>
<th>Aim</th>
<th>Design and Sample</th>
<th>Data Collection</th>
<th>Data Analysis</th>
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<tbody>
<tr>
<td>Tuffrey-Wijne et al.</td>
<td>United Kingdom</td>
<td>A review of the literature on palliative care and end of life care for people with intellectual disabilities and their families</td>
<td>Literature review of 45 sources</td>
<td>Semi-structured interviews</td>
<td>Thematic analysis</td>
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<td>Issues and the difficulties experienced by palliative care staff in relation to the provision of palliative care services for people with intellectual disabilities and their families</td>
<td>Qualitative: 32 palliative care professionals</td>
<td>Thematic Analysis</td>
<td>Identification of family needs</td>
</tr>
</tbody>
</table>

**Outcome/Findings:**

- Identification of family needs
- Importance of service planning
- Importance of service access
- Palliative care services
- Needs of family members
- Communication between family and staff
- Diagnosis and symptom of people with intellectual disabilities
- Confidentiality and privacy of people with intellectual disabilities
- Role of the care team and staff
- Sources of support from multidisciplinary professionals

**Table 2**
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) Permeable Interaction
(5) Common ground
Themes - (1) Partnership
Successful philosophies to be shared between practices
interdisciplinary and interprofessional
Search for new balance
experience of supporting disabled and family caregivers
Meaning of the phenomenological
Community
To provide
Hermeneutic semiotic
Qualitative Hermeneutic
Focus groups and semi-structured interviews
Review
Not applicable
Not applicable
Not applicable
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
Relationship between practices (2) shared learning (3) support and empowerment (4) support and empowerment and family and social care professions supporting disabled and family caregivers
Community
to care education for health interdisciplinary and interprofessional
(2a, b, c)
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/disability required with supporting the carer coping with the aftermath.


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 disabilities requires increased teamwork and fostering of collaborative relationships among professionals and people with disabilities. Joint decision making, cooperation and shared care in the best interests of the person should care in the best interests of the person.
Tuffrey-Wijne et al. (2016)

United Kingdom: involving experts from 15 European countries

To define consensus

Mixed Methods Design (1) Literature review of palliative care services; (2) Delphi rounds to evaluate norms (3) Online survey (4) Recommendations from taskforce

Statistical analysis for quantitative components

Norms were inclusive of: care needs; recognition of palliative care need; needs assessment; involving important people; support for family carers; preparation for death and support in bereavement; education and training for palliative care.