

WHAT IS THE CURRENT EVIDENCE REGARDING THE IMPACT OF THE END OF LIFE FOR INFORMAL CAREGIVERS?

An integrative review of
the literature

Prepared by LifeCircle
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LifeCircle is a national social enterprise whose purpose is to profoundly change the experience and impact of dying, by supporting the people that are living this experience.

We believe that the vision of an Australia where dying is more openly discussed, better prepared for and less institutionalised, and where carers are more strongly empowered and consequently more resilient, is worth striving for.

Death is a natural part of life that can be openly discussed and prepared for. Yet death is a taboo subject. We don't talk about it. We avoid it. People need to relearn the skills to die well, both practically and philosophically

LifeCircle's work has two critical areas of focus.

Firstly, we connect people who are caring for a dying family member or friend with the information, advice, support and resources they need to profoundly change their experience of dying.

Secondly, we enhance the capacity of carers and families to care for themselves, care for each other and care for the person dying and make clear and well informed choices about end of life matters.

We do this through a range of strategic partnership agreements with organisations which share our belief.

Success for LifeCircle centres on building community capacity around death and dying. Through our strategic partnerships we seek to share our philosophy and our empathetic view on death with all Australians, so that they are better supported while caring for someone who is coming to the end of their life.

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What is the current evidence regarding the impact of end of life for informal caregivers? An integrative review of the literature.

ABSTRACT

Background: The end of life presents considerable challenges for informal caregivers - i.e. family, friends or significant others providing non-paid care - with considerable implications for their quality of life, psychosocial wellbeing, participation in leisure and work, and eventually, their capacity to cope with dying, death and bereavement. While the focus of end-of-life care is often placed on the dying person, informal caregivers are also significantly impacted on throughout the dying process, and their needs and experiences must inform broader care and support practices at the end of life. Current evidence, as reflected in peer-reviewed, published studies, has been gathered across a diverse range of service, illness and cultural contexts, requiring a systematic overview and synthesis of current evidence regarding caregiver needs and experiences. Such an evidence-base will be critical to revealing the broader impact of the end of life on informal caregivers, as well as provided a basis for developing future interventions targeting caregivers and aimed at enhancing preparedness.

Method: We undertook an integrative review of the available literature providing evidence regarding the multiple impacts of the end of life on informal caregivers. This was restricted to studies published in English from Australia, USA, Canada, and UK within the last decade (2005-2015), and included the following scholarly databases: Scopus, PubMed/MEDLINE, CINAHL, Health Source, AMED and Sociological Abstracts. Articles were selected based on their focus on caregiver experiences and/or needs at the end of life. These articles included: empirical studies based on primary data collection; studies including secondary data analysis; articles designed to inform policy and/or practice; and, existing review articles. Analysis of research articles was then limited to empirical studies involving primary or secondary data analysis.

Results: A total of 57 papers were identified and systematically reviewed for crosscutting themes. Findings from these studies were extracted, reviewed and grouped according to four key themes: The roles and experiences of informal caregiver and caregivers; the support needs of informal caregivers, the impact of the end of life on informal caregivers; and, levels of and importance of preparedness for informal carers at the end of life.

Conclusion: Considerable international research evidence exists indicating the multiple impacts (i.e. psychological, social, economic) of participating in caregiving at the end of life. While there is considerable evidence that experiences of caring for people who are dying may have positive aspects, there is a broad, cross-cultural evidence base illustrating needs are

often unmet, resulting in negative outcomes (e.g. higher levels of psychological trauma and suffering, incapacity to participate in work or family life). Our review of current international evidence provides a strong rationale for greater community-based and service provider support for informal caregivers. The published evidence illustrates the importance of preparedness in promoting resilience and coping amongst informal caregivers. Finally, it indicates that wider socioeconomic influences (i.e. economic conditions, family structures) and forms of disadvantage may be increasingly challenging people's capacity to provide informal care to the dying, suggesting an urgent need to develop systematic community-based interventions to improve understanding, support and preparedness. There are also considerable gaps in the existing evidence base around informal care for the dying, including a lack of research completed in the community settings, providing only a partial view of contemporary caregiver needs and experiences.

INTRODUCTION

The end of life offers considerable challenges to individuals, families and communities, offering diverse and lasting impacts across illness contexts and socio-demographic groupings (i.e. age, class, education, gender and geographic location) (Aoun et al. 2005a, 2005b; Broom, 2015; Funk et al. 2010; McNamara & Rosenwax, 2010). The last 12 months of life in particular offers a plurality of physical, emotional, psychological and economic challenges, presenting potentially the most significant 'life event' for many Australian families (Grande et al. 2009; Hudson et al. 2010; Maguire et al. 2012). Informal caregivers – i.e. family, friends or significant others providing non-paid care – often hold much of the burden at the end of life, offering those who are dying considerable emotional, practical, spiritual and/or economic support (Aoun et al. 2005a; Grande et al. 2009; Stajdujar et al. 2010). This care comes with considerable impact (both positive and negative) on their own lives (Gaugler et al. 2008; Jo et al. 2007; Wong & Ussher, 2009).

While considerable Government, private sector and out-of-pocket resources are invested in formal, clinical care for the dying (Docherty et al. 2008) - particularly symptom control, amelioration of pain and suffering (i.e. in the home or clinic) - few resources are currently committed to supporting informal caregivers' multifarious needs. In part this is a product of a hitherto limited understanding - and evidence base - regarding the wide-ranging impacts of the end of life on informal caregivers (Bee et al. 2008). Furthermore, there remains a problematic cultural tendency in many OECD countries to withdraw from, or avoid, addressing issues related to human mortality beyond managing the immediate disease and/or health deterioration (i.e. what has been described as the 'death taboo') (Broom, 2015; Clarke et al. 2010). Add to this the fact that the socioeconomic environment in Australia – and in other OECD countries – is increasingly challenging for informal caregivers, with increasing demands for dual-income households and limited access to time to commit to traditional caring activities (Aoun et al. 2005a; Gaugler et al. 2008). The experience of informal caregivers is thus rapidly changing in line with global and local shifts in willingness and opportunities to engage in informal care activities at the end of life (Broom & Kirby, 2013). This makes it crucial that efforts are made to develop a rigorous evidence-base regarding the evolving impacts of dying on caregivers, and that we develop targeted resources to address the unmet needs of informal caregivers within our communities.

While a range of targeted reviews (e.g. Bee et al. 2008; Funk et al. 2010; Grande et al. 2009) have been completed on specific aspects of informal caregiving at the end of life, there are no up-to-date, broad-based integrative reviews of contemporary informal caregiver experiences and needs. This review provides the basis for an evidence base that can facilitate,

in conjunction with data collected from community settings, the development of resources (training and educational interventions) that can assist in better meeting the needs of informal caregivers. In order to develop such resources, an evidence base around impact and experiences is a first critical step.

BACKGROUND

The value of informal care and caregivers

Informal caregivers provide a critical source of emotional, social, spiritual and economic support to people who are dying. The recent shift in palliative and end-of-life care settings from the individual to the 'family' as a unit of care reflects this growing recognition of the crucial role of informal caregivers in the pursuit of the 'good enough' death (McNamara, 2004). That is, the qualities and experiences of informal caregivers are recognised to have a direct relationship to the overall experience of dying (Empeno et al. 2011; Grande et al. 2009). In this way, informal caregivers should be viewed as actively 'working' in conjunction with clinical, formalised caregivers to offer comfort to those who are dying, and supporting (albeit often indirectly) symptom relief and amelioration of pain and suffering (Hansen et al. 2012; Penrod et al. 2011; Wolff et al. 2007; Yu et al. 2014). In turn, it is increasingly recognised that the active participation and experiences of informal caregivers are closely related to how satisfactory the dying process is (for all stakeholders) (Aoun et al. 2005; Empeno et al. 2011; Grande & Ewing, 2009; McNamara, 2004). Put simply, engaged and well-supported informal caregivers improve the experience of dying. In economic terms, well-supported informal caregivers potentially reduce the burden on formalised healthcare services, reduce the need for in-patient or out-patient palliative care services, and reduce the likelihood of unnecessary presentation to hospital when close to the end of life (Aoun et al. 2005a; Yu et al. 2014). The contributions of informal caregivers, and when well-supported, may in turn facilitate dying at home (if appropriate, and desirable for all stakeholders, see Grande & Ewing, 2008) (Brazil et al. 2005; Gomes & Higginson, 2006), recognising that dying at home is the desire of many patients but is often not achieved. Despite the value of informal care and caregivers, there is growing awareness that this may often be at odds with the level of Government and private investment in supporting them during the dying process. While informal carers may indeed 'add significant value' to the end of life, this may also be associated with (increasing) costs associated with such roles (Aoun et al. 2005a; Brazil et al. 2009; Hoefman et al. 2015; Kenny et al. 2010). Here we provide an overview of some of those multifarious costs, and as documented in recent research.

Challenges, opportunities and the potential burden of informal care

As we will illustrate in the results of this review, there is considerable evidence regarding the multifarious challenges associated with providing informal care in end-of-life contexts, and while limited synthesised evidence has previously been available, these range from physical, psychological, spiritual, social to economic (Brazil et al. 2013; Carduff et al. 2013; Dubenske et al. 2008; Jo et al. 2007; Kessler et al. 2005; McGrath et al. 2006; Sloss et al. 2011; Terry et al. 2006). Informal care in end-of-life contexts - depending on the person being cared for, their

illness context, and stage in life - comes at considerable cost to the person delivering care, with potential ripple effects across different spheres of caregivers' lives (i.e. engagement in work, capacity for leisure, quality of relationships, participation in family life) (Gaugler et al. 2009; Lewis et al. 2014; McNamara & Rosenwax, 2010; Terry et al. 2006). While informal caregivers may indeed cherish participation in the dying process, this can be offset by the rising 'costs' of participation in informal care, and moreover, lack of formalised support and thus preparedness for the dying process (Boquet et al. 2011; Empeno et al. 2011; Hoefman et al. 2015; Kenny et al. 2010). Thus, there is an urgent need for an evidence-base - and synthesis of existing data - that captures the varied impacts of participating in the dying process for informal caregivers (and across different spheres of people's working, personal and social lives). This needs to take place with recognition that the end of life presents both opportunities and challenges, and that informal caregivers' experiences are shaped by current and evolving structural and socioeconomic conditions within which care is given (including formalised support for caregivers, or lack thereof).

Caregiver needs and the importance of preparedness

In addition to a focus on the current burden, or key challenges, for informal caregivers, there is a need for an emphasis on informal caregiver needs and the dynamics of preparedness for death (Hebert et al. 2006a). *Anticipating* the range of caregiver needs, rather than *reacting* to psychological distress, illness or longer-term costs of grief/bereavement, is the cornerstone of quality support for informal caregivers (Hebert et al. 2006b; Hudson, 2006; Parkes & Prigerson, 2013; Waldrop et al. 2005). Preparedness for the dying process means service providers, families and communities *anticipating* future needs, ensuring awareness, and encouraging openness in discussions about dying (including preferences and decision-making) (Burns et al. 2015; Dumont et al. 2008; Clarke et al. 2010; Waldrop, 2006). This review provides significant synthesised evidence around the importance of caregiver preparedness and open discussions about dying. Preparedness, we note, is often limited by persistent cultural taboos (Broom, 2015), leaving informal caregivers (and patients/people themselves) to confront challenging emotional and spiritual issues too late or without adequate support (Cherlin et al. 2005; Dumont et al. 2008; Foran Lewis, 2014; Waldrop et al. 2005; Williams et al. 2014). Thus, caregiver needs and the dynamics of preparedness interplay with preparedness requiring early disclosure of needs and concerns on the part of both caregivers and for those people who may be themselves moving toward the end of life. Here we provide a review of international evidence around the experience of, and importance of, preparedness (among other spheres of the end of life) to provide a rationale for supporting and enhancing this within a range of end of life contexts.

METHODOLOGY

A comprehensive review of research on informal caregiving in end-of-life contexts was conducted in July 2015, using a systematic approach which included several inclusion and exclusion criteria. We began by searching using keywords in a series of major academic databases: Scopus, PubMed/MEDLINE, CINAHL, Health Source, AMED and Sociological Abstracts. The following keywords were used (in isolation and in combination) to locate as many relevant articles as possible: informal/family/spouse/non-kin care/carer/caregiver/caregiving + end of life/end-of-life care/palliative/palliation/terminal/ (advanced) cancer. The keyword searches were further refined by year of publication (2005-2015), and language (published in English). Keyword searches within the databases listed above yielded a total of 487 articles. Each article's title, abstract, and country of origin was then reviewed, to exclude irrelevant articles. 84 articles met the inclusion criteria, and were exported into folders as pdfs (an electronic file containing these pdfs is provided). Of these 84 articles, 57 were original research articles, 21 were review papers, and 6 were commentary, editorial or theoretical in their focus. In the results section below, the focus is on the 57 original research articles. However, consideration has been given to other types of article, all of which have been included in the reference list below.

OVERVIEW OF ARTICLES

Table 1 shows a descriptive summary of the key methodological features of the articles. We identified 57 articles fitting the inclusion criteria. Studies reported within these articles focused on data collected from Australia (n=10), UK (8), USA (26) and Canada (13). While methodological approaches varied, a majority of studies were qualitative in their approach (n=39), with quantitative or mixed-methods studies, including large cross-sectional survey data also included. All of the studies had some focus on informal caregivers, either as the sole focus of the study, or as part of broader studies including the experiences or perspectives of multiple stakeholders (usually including patients, and health professionals or health service providers). Few of the articles considered or discussed definitional issues. Rather, informal caregivers were self-identified or identified by patients or health service staff. In the vast majority of studies, the informal caregiver from whom data was collected was identified as the primary caregiver (however, such identification was based on service records and interrogation of the criteria for 'primary caregiver', as with 'informal caregiver' or 'family caregiver' was not included in any depth in any of the articles). Notably, non-kin informal caregivers were not explicitly noted for inclusion in any of the studies.

RESULTS

During the review of the articles, four relevant and predominant themes emerged: the character of the *roles* of informal carers (separated here according to experiences of caregiving and relationships, and coping and decision-making); the *needs* of informal caregivers; the *impact* of informal end-of-life caregiving; and, *preparedness* and *communication* around death, dying and bereavement. In this section, we outline and summarise the findings from respective articles within each of the themes.

Roles: Experiences of caregiving and relationships, coping and decision-making

Many of the studies included in this review included amongst their aim and/or objective 'outlining, describing or categorising' the roles played by informal EoL caregivers. Tables 2 and 3 provide details of the aims, methodologies and findings of these particular articles. Approximately 50% of these studies were focused on active/current caregivers, with the remaining 50% focused on the retrospective accounts or recall of caregivers following bereavement.

A common finding from qualitative studies was the relational aspect of caregiving; specifically, the qualities of the relationship between the caregiver and the dying person. While many of the studies were cross-sectional (and thus gained a snapshot of experiences at a single point in time), findings frequently revealed the dying process as fluid, changing over time, fraught with uncertainties, and requiring a close relationship between the informal caregiver and the care recipient (e.g. Edwards et al. 2012; Jo et al. 2007). For example, Burns et al. (2015), in an Australian study, revealed the ways by which caregiver experiences are often much worse than expected/anticipated, linking expectations and experience to the forms of care provided, and the length of the caregiving experience.

- *In essence, this body of evidence indicates that caregivers may not fully understand the nature of their role until well into the process of providing care, offering considerable potential for lack of preparedness, lack of coping and incapacity to fulfil desired caring role/s.*

Studies also focused on the lived experience of caregiving, providing insight into the day-to-day perspectives and behaviours of informal caregivers. For example, Penrod et al. (2011; 2012) revealed the ways by which caregivers sought to retain a sense of normalcy in their lives despite their intensive caring duties, highlighting the importance of support to assist caregivers' in achieving normalcy in everyday life. This was particularly evident as illness or ill health progressed, and as the dying process drew closer (and thus caring duties increased). In contrast, Wong and Ussher's (2009) Australian study drew attention to the positive aspects of informal caregiving at the end of life, highlighting the benefits and rewards as

perceived by bereaved caregivers. A number of studies focused on the roles of caregivers as primary decision-makers rather than merely 'supporters'. Quinn et al. (2012) categorised family caregiver roles to highlight the various, and shifting, roles family members play in informal end-of-life care. These included: primary caregiver, primary decision-maker, family spokesperson, out-of-towner, patient's wishes expert, protector, vulnerable member, and health care expert.

- *This evidence highlights the importance of recognising the multifaceted roles of caregivers, and varied responsibilities across families, and that providing comfort and support is only one of a wider range of potential activities (e.g. financial or legal affairs).*

The studies also revealed the gendered, geographical and cultural mediation of caregiving. An example is the US study by Fromme et al. (2005) revealing the additional support needs of men who are informal caregivers. This includes recognition that men are less likely to report their own struggles, and are more likely to use fewer words in describing their own and the dying person's circumstances. Read et al. (2007) explored daughters' experiences of turmoil in the caregiving role, particularly given cultural norms for dependence of female family members in the provision of care. Studies by Brazil et al. (2009) and Gaugler et al. (2011) revealed that females generally experience greater caregiving strain, exhaustion and fatigue than males, and that caregiving tasks were distinctly gendered (for example, females more likely to take on personal care tasks and instrumental roles). Donova et al (2011), in a Canadian study, emphasised the importance of religious beliefs and cultural values in shaping the coping capacity amongst caregivers. Other work reflected the importance of accounting for issues around existing disabilities and how such existing challenges may compound, or at least offer unique, caregiving needs at the EoL (Wolff et al 2007). Finally, Hansen et al (2012) found that rural caregivers faced considerable and unique advantages and disadvantages, in EoL contexts, once again highlighting the need for targeted support.

- *This body of evidence outlines the importance of understanding caregiver roles as highly differentiated according to gender, place, health, disability status and other biographical characteristics, and the importance of recognising that not all caregivers will provide, or be expected to provide, equal levels of care within families.*

Finally, in terms of caregiver roles, the evidence clearly illustrates that caregivers in end-of-life contexts face considerably greater challenges than those caregiving in other contexts. As outlined by, for example, Wolff et al. (2007), EoL caregivers provide significantly higher levels of assistance/care and experience more challenges and strains compared to caregivers in non-end-of-life contexts.

- *This evidence reinforces the importance of not merely assuming traditional models of, or approaches to, 'caregiver support' can be utilised in this specific context, but rather that supportive practices must be developed that specifically target the core issues facing this unique population.*

Needs/Support of informal caregivers in end-of-life contexts

Twenty one of the articles included aims/objectives, or findings/discussion, focused on the specific needs of informal caregivers in end-of-life contexts. For each of these articles, needs were directly related to support for caregivers, most commonly in relation to improving health service provision to better meet the needs of informal caregivers. Table 4 provides details of the aims, methodologies and findings of these particular articles. Four domains emerged from empirical studies related to the needs of informal caregivers: information/communication, service provision, service support (i.e. health and community) and social support (i.e. encompassing emotional, financial and practical support). Caregiver needs were in turn separated into two broad categories: a) need for support in caring for the patient (i.e. pain management, assistance with physical work, practicalities, decisionmaking, information around how best to provide care for the patient), and b) need for support *in relation to coping*, caregiver identity, grief and loss (i.e. emotional support from service providers, family, friends, bereavement support). Needs relating to the care recipient included providing social and emotional support, and practical care needs (e.g. information about services, whether care can be physically provided at home, wheelchair access, lifting, bathing). Needs relating to the caregiver were predominantly focused on bereavement needs/support, but also included issues around identity, social support and relationships.

There is a significant body of evidence outlining the critical, and often compounding, needs of informal end-of-life caregivers. The evidence overwhelmingly points to the need for greater support. The body of evidence is outlined in detail on Table 4. To draw on several examples, the study by McIlfratrick (2007) identified a greater need for social, psychological and financial support for informal caregivers, pointing specifically to the importance of the need for a sense of choice and greater levels of information. Sloss et al. (2012) revealed the lack of formal health service engagement with issues around spirituality and caregiverspecific emotional needs/experiences. Terry et al. (2006), in their Australian study, outlined informal end-of-life caregiver concerns, including: poor access to services and support; needing more help with practical issues; and, the absence of sufficient information about the patient's illness and/or prognosis. Clayton et al's (2005) study found that patients and caregivers often have very different informational needs, and that those of the caregiver are often left unmet by health professionals. Several studies highlighted the additional needs of caregivers in home-based settings, pointing to the dangers of emotional and informational isolation for caregivers dependent on home care services. In their Canadian study, Jo et al. (2007) found that while

caregivers appreciated home palliative care services, they also felt the need for additional support. Seamark et al. (2014) highlighted the characteristics associated with enabling more supportive and positive caregiver experiences, particularly pointing to the needs of home-based caregivers. Joyce et al. (2014) highlighted the lack of support for informal caregivers for patients receiving hospice care at home, particularly in managing medications.

- *This evidence highlights the current challenges related to caregivers feeling ‘uninformed’ due to a lack of information and engagement from those providing services to them. Such experiences result in a sense of a lack of ‘informed choice’ within the caregiving process, reducing their capacity to cope and care for a loved one at home. The implication of this evidence is that caregivers need integrated emotional, social and spiritual support, as well as additional information on available services, prognosis, and the likely realities of the dying process. Finally, they require more support to achieve continuity between formal and informal care.*

Several studies included in the review focused on examining the ‘cultural correlates’ of caregiver needs, aiming to outline the needs of caregivers from particular sociodemographic contexts. Indeed, a number of studies included a focus on variations in access and use of formal health services and supportive care resources, revealing important 11 cultural, religious and geographic variabilities in end-of-life care experiences (Brazil et al. 2013; Lewis et al. 2014; McGrath et al. 2006; McNamara & Rosenwax, 2010). In Australia, Lewis et al. (2014) pointed to the dangers of compounded vulnerability in terms of networks and relations of support for a lower socio-economic status population, while McGrath et al. (2006) found a serious need for Indigenous respite services for informal end-of-life caregivers in rural Australia. McNamara & Rosenwax’s (2010) study, also based on the Australian context, identified a range of factors which showed that some informal end-of-life caregivers are more vulnerable than others. However, in their study in the UK, Kessler et al. (2005) highlighted the universal needs of end-of-life family caregivers, showing that there are shared expectations and uncertainties across social groups.

- *This evidence outlines the ‘social justice’ implications of caregiving, including the challenging fact that those who are already most vulnerable are likely to face the most challenges receiving and providing care in end-of-life contexts. This evidence raises the vital importance of targeted resources for those who are likely to face, or are already struggling with, social and economic disadvantage. This includes recognition that the needs of the disadvantaged will be different than those of the ‘general population’.*

Studies also provided insight into caregiver experiences as the care recipient’s illness trajectory continues, the recipient’s condition deteriorates, and their needs increase. McCurry (2013), in a qualitative study examining decision-making by informal caregivers, found that as the disease progressed, informal caregiver decisions increased in their complexity and

intensity, highlighting the increasing burden on informal caregivers over time. In their UK study, Carduff et al. (2013) found that informal caregiver needs become less manageable as the person's health deteriorates, while Dubenske et al. (2008) found that caregiver needs varied significantly according to experience of caregiving, and illness stage.

- *This evidence highlights the relational and temporal dimensions of end-of-life informal caregiving, where caregivers' often gradually take on increasing care duties and responsibilities, and where both the patient and caregiver's needs invariably increase over time as the dying process progresses.*

The impact of caregiving on informal caregivers

The third emergent theme within aims and findings of empirical articles was the impact of caregiving on informal end-of-life caregivers. Within this thematic focus, articles reported predominantly on quantitative studies and health service interventions aimed at outlining the impact of caregiving on physical and mental health, quality of life, and bereavement experience. The qualitative studies included (n=5) focused on the lived experience of caregiving and carers' subjective accounts of burden and benefits. The aims, methodologies and findings of these studies are listed in Table 5.

Several key studies aimed to assess the impact of caregiving in relation to service provision, where support-based interventions held the potential to decrease caregiver burden and improve wellbeing. Hoefman et al. (2015), focusing on health and quality of life 12 indicators, found that caregiver health was associated with both the health of the care recipient, and the duration of caregiving, pointing to the increasing strain and burden of caregiving as it continues. Kenny et al. (2010) pointed to the need to recognise and support informal end-of-life caregivers in order to avoid potential health impairments as a result of caregiving. Williams et al. (2008) found that social support for caregivers was linked to better physical health, while Empeno et al. (2011) found that additional service provision reduced informal caregiver overload. Moreover, that supporting caregivers was beneficial for not only caregivers, but also patients and service providers. Francis et al. (2009) found that high quality relationships between the informal caregiver and the patient, family and health professionals resulted in lower burden for informal caregivers.

- *This evidence captures the most important dimension of the 'caring dyad' – that caregiver psychological and physical health has a direct relationship to the quality of life of those who are dying. That is, the healthier the caregiver, the better the care is, and the better the experience of being cared for is. This evidence outlines the direct benefits (and a solid rationale) for greater formal and informal social support for caregivers.*

Several of the studies highlighted the significant and serious flip-side of the above dynamic – the considerable negative impacts for caregivers at the end of life. For example, studies

such as Williams et al. (2014) found that end-of-life informal caregivers experienced a higher proportion of negative impacts on their social and activity patterns compared to nonend-of-life caregivers, highlighting the potential for considerable and progressive social isolation in end-of-life contexts. Zapart et al. (2007), in their Australian study, highlighted the effects of caregiving on social and family relationships, the restrictions on work and leisure, and the variance in emotional reactions to caregiving and the end of life. Williams et al. (2008) found that caregiver emotional strain was associated with age, gender, education, financial burden, and the extent of caregiving involvement. In a US study of hospice informal caregivers, Boquet et al. (2011) found experiences of fatigue, stress, guilt and loss of identity were common. There was limited evidence of the potential for positive impacts on caregivers. Jo et al. (2007) outlined some of the positive impacts for caregivers, while noting the reported need for additional caregiver support. Wong and Ussher (2009) outlined the positive meanings associated with informal caregiving, highlighting satisfaction as a valuable consequence of providing care.

- *This evidence captures a worrying international trend – that of caregiving at the end of life as considerably fraught in terms of physical, emotional, social, relational, financial and practical impacts. These experiences may indeed be situational and a product of lack of resources invested in informal caregiving. In this way, such outcomes may be open to considerable change with investment in greater levels of caregiver support. Regardless they illustrate the overwhelming burden that many caregivers experience.*

Several studies investigated the impact of caregiving in relation to bereavement, in line with a range of (usually formal, health service driven) support services offered to caregivers in end-of-life contexts. Cherlin et al. (2007) discovered various barriers to accessing and utilising bereavement services, showing that informal caregivers were often too stressed or busy to prioritise or be receptive to formal bereavement support. McLaughlin et al. (2007) found that greater levels of pre and post bereavement support was needed to support caregivers at a times of increased strain (i.e. close to death and immediately following 13 death). Waldrop (2006), collecting data from caregivers pre- and post-bereavement, revealed informal caregiver grief as highly influenced by social context and relationships with family and friends.

- *This evidence outlines the difficulties faced by health services in supporting informal caregivers following bereavement, highlighting the need for earlier (and communitybased) interventions to support caregivers, and the need to include caregivers with the ‘unit of care’ [rather than individual patient/person].*

Communication and preparedness for the end of life

The final emergent theme within the empirical studies is the considerable value of communication and preparedness for caregivers in end-of-life contexts. More than 50% of all the studies included provided recommendations for practice and resource development regarding enhanced communication between formal (health) and informal caregivers. In the majority of cases, such communication was linked (implicitly or explicitly) to better equipping and preparing caregivers for the inevitable death of their loved one. Research explicitly aimed at investigating or exploring communication or preparedness was lacking (with the exception of Cherlin et al. 2005; Clarke et al. 2005; Waldrop, 2005). Table 6 provides details of the aims, methodologies and findings of articles included in this review which include some focus on preparedness and communication.

There is considerable evidence that levels of preparedness are highly inadequate for caregivers in end-of-life contexts across the cultural contexts examined here. Hebert et al. (2006b) found that almost 25% of informal caregivers were not prepared for the death of their loved one and that unprepared informal caregivers had more depression, anxiety, and complicated grief symptoms. A very recent Australian study by Burns et al. (2015), outlined worse than expected experiences of caregivers in end-of-life contexts, highlighting the need for communication of expectations to improve experiences. Cherlin et al. (2005) also found that ineffective communication at the end of life results from the dual problems of physicians' unwillingness to discuss and family caregivers' difficulty in accepting the dying process. Holtslander et al. (2005) documented the important of retaining hope - and the negative impact of eroding hope - as a core aspect of communication. That is, that preparedness for dying does not mean that hope cannot be incorporated within clinical/patient and clinical-carer communication. This needs to be placed beside evidence from Hudson (2006) that outlined the importance for family caregivers in receiving factual, timely and accurate information on prognosis and time-till-death expectations to prepare them for the future. Clarke et al. (2005) outline the importance of communication about advance care planning as a vital facet of facilitating preparedness and retaining a sense of choice in care practices. Donovan et al. (2011), in their study, highlighted cultural factors (including barriers) in experiences of caregiving and bereavement, highlighting the significance of acknowledging and incorporating cultural attitudes towards communication and care-seeking behaviours. Waldrop (2005) outline the value of clear communication, information and guidance for formal caregivers. This evidence outlines that there are significant variations regarding people's willingness to talk about death/dying and find out more about EoL care, and that any resources and support provided must acknowledge the desires of different members of the community (e.g. older members of the general public and ICGs).

- *This body of evidence points to the critical importance of addressing the dynamics of preparedness across multiple stakeholders, and that awareness and communication is not*

merely about the caregiver, but is the responsibility of many different people (i.e. doctors, nurses, social workers, psychologists, volunteers, families and patients). It points to the importance of raising the issue of death and dying as early as possible over the course of aging and ill health, opening up lines of communication across stakeholders, and thus softening the 'news' of the dying process. Such strategies would allow people more time to adjust. Finally, this illustrates that communication and preparedness are situated in cultural practices and norms, and highlight the importance of recognising that each individual and family will require different forms of information and respond in varying ways to support, information and advice.

DISCUSSION

The review provides an overview of the evidence produced in Australia, USA, Canada, and UK over a ten-year period, and reveals the considerable work that has been done on caregiver experiences in end-of-life contexts. We have synthesised this evidence in terms of its engagement with particular facets of end-of-life caregiving. These include *roles*, *needs*, *impacts* and *preparedness*. These issues are each important, discrete, but also interwoven. Without an understanding, for example, of diversity within the caregiver role, there is limited capacity to identify needs and promote preparedness. Each of the Tables provided in this review outline the full evidence-base for each issue. The results of this Review can be encapsulated by 11 key points which cut across these critical end of life issues:

1. There is clear evidence that caregivers make critical contributions to the relative 'success' of the end of life, including supporting and often enhancing the psychological, social, spiritual and economic wellbeing of those they care for.
2. The roles that caregivers play at the end of life, and thus the nature of their supportive care needs, is highly differentiated across individual biographies (i.e. according to gender, age, culture, and geography).
3. Caregivers embark on the process of informal caregiving at the end of life, often without a clear awareness or understanding of what the process will involve.
4. In embarking on caregiving activities without adequate awareness and preparedness, the experience of caregiving has significant costs for carers that are evident well beyond the time leading up to, or the point of, death (i.e. emotional, physical, social and economic costs).
5. The multifarious 'costs' associated with end-of-life caregiving are directly related to the quality of care provided, and the overall experience of being care for at the end of life; specifically, carer psychological and physical health has a direct relationship to quality of life of those who are dying.
6. Lack of current support and care for caregivers reduces the potentially positive benefits of being involved in care at the end of life.
7. Caregivers require emotional, social and spiritual support, more information on available services, communication around the realities of the dying process, and more support to manage formal and informal care and continuity of care.
8. Evidence shows the critical importance of a 'social justice' model of intervention and care, whereby those who are already disadvantaged are targeted as they are likely to face additional challenges within end-of-life contexts.
9. Evidence clearly shows the temporal dimensions of caregiver needs, illustrating the importance of early intervention, support and communication, and the 'cascading' costs of caregiving as the end of life nears, and if inadequately supported.

10. There is evidence of clear international trend in underinvestment in caregiver needs and support, with indications that the 'caregiver experience' may be open to considerable change with investment in greater levels of caregiver support.
11. In addressing preparedness and encouraging communication, *all participants* in the dying process must be engaged as active stakeholders in communication (i.e. doctors, nurses, allied health clinicians, volunteers, families, patients) and in understanding and supporting the needs of caregivers, not just the people who are dying.

CURRENT GAPS IN RESEARCH AND POTENTIAL FUTURE DIRECTIONS

While the available evidence highlights a wider range of caregiver experiences, needs, burden and support, there are a number of gaps in the literature. Some of these of which we identified in this review are as follows:

1. There is little or no research beyond that conducted in formalised healthcare settings.
2. There is an overemphasis on clinical criteria and methods of assessment of 'functioning' and 'factual awareness' (i.e. knowledge, understanding, communication) rather than an emphasis on forms of support beyond the informational (i.e. emotional, spiritual support predominantly sought from family, friends, loved ones, not health services or professionals).
3. A large proportion of the current evidence relates specifically to cancer, and there is an urgent need to extend to other health and illness contexts.
4. Future research should focus more on interpersonal relationships and how patients and caregivers communicate regarding their fears, hopes and needs at the end of life.
5. Further work is needed that conceptualises caregivers as both providers and recipient of care.

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Table 1: Summary of key methodological features of articles (total articles = 57)

Characteristic	n (%)
Patient conditions	
Cancer	14 (25)
Other (heart failure, MS, dementia)	4
Not specified, EoL service recipients	39 (68)
Caregiver type	
Family	27 (47)
Spouse	2
Child	1
Grandchild	1
ICGs (not specified)	30 (53)
Caregiver status	
Bereaved	17 (30)
Current/active	27 (47)
Both	6
In transition	1
Unspecified	6
Date collection	
Qualitative	39 (68)
Interview	33 (58)
Focus group	5
Observation	1
Workshop	3
Quantitative	32 (56)
Survey/structured interview	25 (44)
Clinical measure/instrument/tool	5
Analysis of records	2
Mixed/multi-methods	14 (25)
Country	
Australia	10 (18)
UK	8
USA	26 (46)
Canada	13 (23)

Table 2: The roles of informal caregivers: experiences of caregiving and relationships

Author, year, country	Aims	Study setting/design	Sample and sample size	Methods/analysis	Relevant findings	Weaknesses/appraisal
Boquet et al. 2011, USA	To provide insight into the role of grandchildren as hospice ICGs	Qualitative case study approach, phenomenological approach	4 ICG grandchildren, part of a larger study on hospice ICGs	In- depth interviews, intervention workshops; thematic analysis	Emergent themes included experiencing: fatigue, stress, guilt, and loss of the "grandchild" identity.	Small sample. Moves beyond immediate FCG relationship.
Burns et al. 2015, Australia	To analyse the characteristics of ICGs who report worse than expected experiences	Annual random face-to-face cross sectional survey	1628 active EoL ICGs from South Australia	Retrospective, structured interviews; logistic regression analysis	Describes the factors associated with a worse than expected experience (gender, type of care, length of care)	No exploration of expectations that existed. Highlights need for communication of expectations to improve experience
Donovan et al. 2011, Canada	To understand cultural factors in experiences of caregiving and bereavement	Longitudinal qualitative approach, Dutch reformed participants, Ontario	Purposive sample; 5 FCGs (15 interviews in total)	2-5 interviews with each participant over time; qualitative analysis/ coding	3 themes emerged: cultural attitudes towards care, religious beliefs and coping, and culturally-informed care-seeking behaviours	Small sample size. Longitudinal emphasis allows for temporal analysis. Provides insight into the social, cultural and religious context of informal FCGs
Edwards et al. 2012, Canada	To understand decision-making process that occurs between a dying individual and FCG	Qualitative design; Large urban city	Purposive/theoretical sample, 5 patients, 3 FCGs, 9 bereaved caregivers	Grounded theory; constant comparison approach to analysis	Outlines EoL decision-making processes as fluid, changing over time and requiring a close relationship between ICG and recipient	In-depth description of the changing role of FCGs, from a supportive, to a managing role, to eventually taking over care and decision-making completely
Fromme et al. 2005, USA	To examine men's experiences of EoL caregiving, focusing on caregiver strain	Mixed methods approach, secondary analysis	Random sample of bereaved FCGs (n=1384, 29% were men)	Structured interviews (open/closed questions); linear regression; qualitative analysis	Men less likely to report FCG strain/patient distress; men more likely to use fewer words to describe EoL	Points to significance of gender in EoL FCG experience, and potential consequences for care/needs

Author, year, country	Aims	Study setting/design	Sample and sample size	Methods/analysis	Relevant findings	Weaknesses/appraisal
Hansen et al. 2012, USA	To describe perspectives of FCGs' experiences of formal /informal care at EoL	Qualitative, descriptive study; rural, agricultural location	Purposive sample, 23 bereaved FCGs, recruited by hospice staff/funeral directors	Semi-structured interviews, thematic analysis	Findings indicate both benefits and challenges within the rural area	Points to the need for further work in rural settings to explore the complexity of ICG experience at EoL
Holtzlander et al. 2005, Canada	To explore the experience of hope for ICGs of palliative patients	Qualitative grounded theory approach, 2 Canadian cities	10 ICGs living with and caring for palliative patients	Semi-structured interviews, constant comparison and theoretical coding	Highlights value of hope (and the impact of eroding hope) for home-based ICGs in EoL settings	Small sample, cancer overrepresented. Examining experiences during EoL care captures the lived experience.
Jo et al. 2007, Canada	To examine spousal perspectives on home-based PC experiences	Qualitative approach	Palliative care patients and their ICGs, 10 dyads (n=20)	Face-to-face interviews, coding, content analysis	Results show positive and negative aspects of caring; spousal care as relational	Sheds light on unexpected aspects of EoL home care for FCGs, points to need for further support for FCGs
Lewis et al. 2014, Australia	To identify individual, community, and civic networks /relations for a lower SES population	Qualitative study in a lower socioeconomic area	16 patients, 6 ICGs with social/ economic needs and from a lower socioeconomic area	Semi-structured interviews; framework analysis	ICG networks/ relations were small/ fragile; formal services inconsistent, limited practical support	Highlights importance of networks and relations of support. Highlights compounded vulnerability for lower SES populations at EoL
McLaughlin et al. 2007, UK	To explore bereaved ICGs' experience of a Hospice at Home service	Cross-sectional survey design, one region of the UK	128 bereaved ICGs, recruitment through health service	Postal survey; descriptive statistical analysis (SPSS)	Need for practical/ bereavement support, increased awareness of the home service	Points to the need for in-depth qualitative work focused on ICG experience
Penrod et al. 2011, USA	To illustrate variations in FCG trajectories as described by informal EoL FCGs	Qualitative approach, case study	Active or former informal FCGs (n = 46)	Unstructured interviews; analysis of case studies	Emphasises need for "seeking normal" as FCGs work toward achieving a steady state during caregiving experiences	Further understanding of caregiving trajectories. Focus primarily on implications for nursing practice

Author, year, country	Aims	Study setting/design	Sample and sample size	Methods/analysis	Relevant findings	Weaknesses/appraisal
Penrod et al. 2012, USA	To explore the experiences of 46 FCGs of adults suffering a variety of life-limiting conditions	Qualitative, grounded theory approach	Purposive sample of bereaved (n=38) and active (n=9) FCGs	In-depth, face to face interviews, constant comparison approach to analysis	FCGs sought reliable patterns of everyday life while caregiving. FCGs viewed as both coproviders and corecipients of care	Aimed towards improving health care practice. Highlights the value of understanding the progression of EoL caregiving
Phillips et al. 2009, USA	To describe FCGs' constructions of their role in providing care to dying elders	Exploratory qualitative study	Purposive sample of 27 bereaved FCGs	Semi-structured interviews; Constant comparison approach to analysis	4 key themes: centering life on the elder, maintaining normalcy, minimising suffering, and gift giving	Reveals the complex relational aspects of informal care at EoL
Quinn et al. 2012, USA	To describe informal roles of FCGs involved in the process of EoL decision making in ICUs	Ethnographic study in 4 intensive care units in a University Medical Centre over 4 years	Health care clinicians, patients and family members (n=130)	Participant observation with field notes and semi-structured interviews	Reports 9 key typologies of informal caregivers; shows variability in roles	One setting, although different ICUs included). Comprehensive description of some of the roles of FCGs within ICUs at EoL
Read et al. 2007, Canada	To explain the domain of daughters' caregiving experiences	Qualitative study in Newfoundland and Labrador, Canada	Theoretical sample of bereaved women who had provided informal care for a parent (n=12)	Grounded theory approach, in-depth interviews; theoretical coding	Findings exposed 3 types of turmoil (emotional, relational, and societal)	Small regional sample Offers a framework for clinical practice through discussion of potential strategies to limit ICG turmoil
Wolff et al. 2007, USA	To characterize primary ICGs' EoL experiences for care to chronically disabled community dwelling older adults	Primary family caregivers for older adults with chronic disability; from national survey	1149 primary ICGs, stratified by care recipients' survival or death during the following 12 months	Cross-sectional national survey; statistical analysis comparing demographic characteristics with indicators of care	End of life caregivers provided significantly higher levels of assistance and reported more challenges and strains	Large sample, restricted to chronically disabled older adults. Does not address temporal change in care provision. No information on disease profile of patients
Wong et al. 2009, Australia	To explore the positive meanings of providing informal PC at home	Qualitative approach, social constructionist approach	22 bereaved informal cancer carers	Semi-structured interviews, thematic analysis	Benefits and satisfaction derive from providing care at home	Highlights the positive and rewarding aspects of informal care at EoL

Table 3: The roles of informal caregivers: coping and decision-making

Author, year, country	Aims	Study setting/design	Sample and sample size	Methods/analysis	Relevant findings	Weaknesses/appraisal
Conner et al. 2015, USA	To examine EoL caregiving and decision making among blacks from the perspective of ICGs	Qualitative, focus groups, recruitment from black religious congregations in Florida	5 focus groups (number of participants unknown)	Qualitative phenomenological approach	Findings suggest need for support/inclusion of ICGs in the advance care planning process early in the disease trajectory	Recruitment predominantly from worship sites (although some from the wider community). In-depth focus on lived experience
Edwards et al. 2012, Canada	To understand the decision-making process between a dying individual and his/her FCG	Qualitative design; Large urban city	Purposive/theoretical sample, 5 patients, 3 FCGs, 9 bereaved caregivers	Grounded theory; constant comparison approach to analysis	Outlines EoL decision-making processes as fluid, changing over time and requiring a close relationship between ICG and recipient	In-depth description of the changing role of FCGs, from supportive to managing role, to taking over care and decision-making completely
Epiphaniou et al. 2012, UK	To identify coping and support mechanisms for cancer ICGs in order to inform intervention development	Qualitative approach	20 ICGs of home palliative patients, recruitment through community pall care team	Semi-structured interviews; thematic analysis	ICG coping strategies: distraction, mental stimulation, emotional release, looking for positives, disengaging from stress	Clinical nurses led recruitment, also offered support. Suggests potential interventions from health services
Foran Lewis, 2014, USA	To explore the experiences of ICGs seeking formal EoL care for a loved one with dementia	Qualitative phenomenological approach	Purposive sample, 14 ICGs actively seeking formal EoL care, particularly hospice care	In-depth interviews; thematic analysis of phenomena	Five themes: setting the stage for heartbreak, reaching the boiling point, getting through the front lines, settling for less, and welcoming death	Small sample, focus on dementia. In-depth analysis of lived experience of managing informal and formal care. Highlights struggles of ICGs beyond cancer
Francis et al. 2009, USA	To explore association between FCG relationships and FCG burden during treatment	Quantitative design, baseline assessments within a larger RCT	420 FCGs of late-stage cancer patients	Structured telephone interviews; multiple linear regression analysis	Higher quality relationships with family and health professionals linked to lower FCG burden	Cross-sectional data. Points to need for early intervention to ensure quality relationship between FCGs and health professionals

Author, year, country	Aims	Study setting/design	Sample and sample size	Methods/analysis	Relevant findings	Weaknesses/appraisal
Fromme et al. 2005, USA	To examine experiences of men involved in EoL caregiving, focusing on caregiver strain	Mixed methods approach, secondary analysis	Random sample of bereaved FCGs (n=1384, 29% were men)	Structured interviews (open and closed questions); linear regression; qualitative analysis	Men less likely to report FCG strain or patient symptom distress; men more likely to use fewer words to describe circumstances at EoL	Points to significance of gender in EoL FCG experience, and potential consequences for care/needs
Kelley et al. 2013, USA	To describe/organise ICG pain management challenges for home hospice caregivers of cancer patients	Interviews as part of a larger clinical trial in two hospice programs in the Northwestern United States	Purposive sample of 29 ICGs of patients dying of cancer	Total of 87 interviews; Content analysis of secondary data (recordings of caregiver interviews)	Themes: ICG medication and symptom knowledge, communication/teamwork issues, organisational skills, patient-centric Issues	Restricted to secondary data analysis, relatively small sample size
McCurry, 2013, USA	To examine decision making by ICGs of MS care recipients.	Qualitative, exploratory-descriptive research design	6 participants	2 in-depth interviews; qualitative content analysis	Areas of decision-making: healthcare, financial, social, family. Decisions increased in complexity/severity as disease progressed.	Limited sample size and selection. Highlights significant burden of decision-making/management on ICGs
Retrum et al. 2013, USA	To examine for congruence and incongruence between heart failure patients and their informal FCGs	Qualitative design, recruitment through a university hospital	Purposive sampling, heart failure patients and ICGs (17 dyads, n=34)	Semi-structured interviews, constant comparison approach to analysis/ coding	Varying extents of congruence/communication between patients and ICGs	Focus on dyads and relational aspects of experience of managing illness, perceived care needs and EoL issues
Stajduhar et al. 2008, Canada	To describe factors influencing family caregivers' ability to cope with providing end of life cancer care at home	Interpretive descriptive (qualitative) approach	29 active family caregivers	Semi-structured interviews; thematic analysis	Factors influencing ability to cope: FCG's approach to life, patient's illness experience, patient's recognition of ICG contribution, quality of ICG-patient relationship, ICG's sense of security	Cross-sectional (coping abilities may change over time). Participation may indicate that cohort of participants were coping well. In-depth insight into factors that influence ICGs' abilities to cope

Table 4: The needs/support of informal caregivers in end-of-life contexts

Author, year, country	Aims	Study setting/design	Sample and sample size	Methods/analysis	Relevant findings	Weaknesses/appraisal
Brazil et al, 2014, Canada	To examine the support needs for urban and rural FCGs	Cross-sectional design	Purposive sampling, 70 rural and 70 urban FCGs	Telephone survey, statistical analysis (SPSS)	FCG support needs were assessed in 3 domains: informational, tangible, and emotional support needs	Low response rate; bereaved as well as current FCGs. Moves beyond urban settings
Brazil et al. 2005, Canada	To determine ICGs perceptions and preferences about place of care/death	Telephone bereavement interviews in communities in Canada	Convenience sample of 216 bereaved informal caregivers	Quantitative statistical analysis on perceptions of care, satisfaction with services/ experience	Findings suggest ethic of choice for care recipient must balance with consideration of wellbeing of the ICG	Relatively small convenience sample. Highlights the complexity and fragility of preferences for place of death
Brazil et al. 2013, Canada	To compare the experiences of rural and urban FCGs of the terminally ill	Standardised measurement; cross-sectional community-based study	Purposive sample, 100 active ICGs; recruitment through client records	Structured telephone interviews; statistical analysis	Outlines burden and support for rural and urban ICGs, and variations in availability and access/use of formal services	Low response rate, likely that results underestimate burden. Moves beyond urban centres
Carduff et al. 2013, UK	To explore barriers to, and consider strategies for, identifying carers in primary care	Integrated data sources, qualitative approaches	EoL care researchers, ICGs, health professionals	Lit review, Workshop (15 participants), focus groups (n=15 groups of ICGs);	ICGs often identify as relation not carer. ICG needs become less manageable as patient's condition deteriorates	Limited to FCGs. Explores legitimacy for FCG identity; EoL care as a gradual process. Need to recognise ICGs in health services
Cherlin et al. 2007, USA	To explore predictors of and reasons for use and non-use of bereavement services	Prospective cohort study, longitudinal, mixed methods	Primary FCGs (n=161) of patients with cancer	Baseline interviews (2 per FCG); descriptive statistics; qualitative content analysis	Approx. 30% used bereavement services. FCGs not receptive to bereavement services	Highlights various barriers to utilising bereavement services

Author, year, country	Aims	Study setting/ design	Sample and sample size	Methods/analysis	Relevant findings	Weaknesses/ appraisal
Clayton et al. 2005, Australia	To explore views of terminally ill patients, ICGs, and PC HPs on the varying informational needs for patients/ICGs	Qualitative approach	Patients (n=19), ICGs (n=24) recruited from Sydney-based PC services, health professionals (n=22)	Focus groups, interviews, qualitative thematic analysis	Patients and ICGs have very different informational needs. ICG informational needs often unmet by health professionals	Cross-sectional. Highlights complexities around HP management of info for patients and ICGs (e.g. issues around withholding information, consent)
Dubenske et al. 2008, USA	To examine needs across transitions in advanced cancer disease trajectory	Cross-sectional representative report data, needs assessment survey	159 female ICGs (current /former); recruitment through advertising	Survey, needs indicators; statistical analysis	Highlights the varying needs of cancer carers according to experience and illness stage	Only female ICGs; cross-sectional retrospective information. Points to need for more education/ information based interventions
Fleming et al. 2006, USA	To explore association between perceptions of health care and QoL for advanced cancer patients/ICGs	Quantitative study; survey with a comprehensive cancer centre	Patients with advanced cancer and their ICGs, (n=39 pairs)	Baseline survey (by phone or self-completed), including a range of QoL measures; descriptive statistics	Data suggest that patients with advanced disease and their caregivers share similar perceptions and evolve as a "unit of care"	Small sample size; burdensome survey. Highlights importance of ICGs as members of the patient's health care team, and as also in need of care
Jo et al. 2007, Canada	To examine spousal perspectives on home-based PC experiences	Qualitative approach	Palliative care patients and their ICGs, 10 dyads (n=20)	Face-to-face interviews, coding, content analysis	Results show positive and negative aspects of caring; spousal care as relational	Sheds light on unexpected aspects of EoL home care for FCGs, points to need for more support for FCGs
Joyce et al. 2014, USA	To explore factors related to ICGs' support with managing medications for EoL home hospice patients	Convenience-sampled, cross-sectional telephone survey	120 caregivers managing medications, referred by Chicago-based home hospice services	Computer-assisted telephone interviews; statistical analysis, bivariate logistic regression	High proportions of ICGs may not have support managing medications for patients receiving hospice care at home	Small sample size; no exploration of the type/ nature of caregiving duties/time etc.

Author, year, country	Aims	Study setting/ design	Sample and sample size	Methods/analysis	Relevant findings	Weaknesses/ appraisal
Kessler et al. 2005, UK	To determine social class differences in place of death, explore experience of FCGs, and identify inequalities in access to palliative care	Multi-methods approach, focus on SES, location, place of death	Analysis of 960 cancer death records, purposive sample of 18 bereaved FCGs	Cross-sectional survey of cancer deaths; in-depth interviews, framework approach to analysis	Inequality in access/ utilisation of healthcare in terminal illness not prominent in FCG accounts; lowest SES patients more likely to die in hospice	Highlights universal needs of EoL FCGs (expectations, uncertainties irrelevant of social class)
Lewis et al. 2014, Australia	To identify the nature of individual, community and civic networks / relations for a lower SES population	Qualitative study in a lower socioeconomic area	16 patients, 6 ICGs with social/ economic needs and from a lower socioeconomic area	Semi-structured interviews; framework analysis	ICG networks/relations Small/fragile due to nature of conflict and crisis; formal services inconsistent, limited practical support	Highlights the importance of networks and relations of support. Highlights compounded vulnerability for lower SES populations
McGrath et al. 2006, Australia	To develop an innovative model for Indigenous palliative care	Qualitative design, Northern Territory, Aus	Patients, carers, health workers, interpreters; recruited through Aboriginal health workers	72 in-depth interviews; thematic phenomenological analysis	Serious need for Indigenous respite services in rural/ remote areas. Lack of services linked to poorer health outcomes for patients/ICGs	Highlights importance of tackling obstacles preventing local respite services being established in areas close to where patients / carers live
McIlfatrick, 2007, UK	To investigate pall care needs served by healthcare organisation	Qualitative approach, palliative care service, Northern Ireland	Purposive sample with patients and ICGs (n=24), pall care providers, managers	Semi-structured interviews, thematic analysis	Identified need for greater social/ psychological, financial support; and need for choice and information	Focus on needs assessment; moves beyond cancer focus
McLaughlin et al. 2007, UK	To explore bereaved ICGs' experience of a Hospice at Home service	Cross-sectional survey design, one region of the UK	128 bereaved ICGs, recruitment through health service	Postal survey; descriptive statistical analysis (SPSS)	Need for practical/ bereavement support, increased awareness of the home service	Points to the need for in-depth qualitative work focused on ICG experience

Author, year, country	Aims	Study setting/design	Sample and sample size	Methods/analysis	Relevant findings	Weaknesses/appraisal
McNamara et al. 2010, Australia	To explore perceptions of health services support for EoL ICGs and role of support in shaping FCG health	Mixed methods: administrative data and qualitative methods	1071 ICGs (retrospective primary data collection)	Administrative records data, semi-structured telephone interviews; statistical analysis, triangulation	Indicates which ICGs are more vulnerable than others; lack of support associated with non-preferred place of death	Retrospective study, recall bias potential. Highlights the need for support to targeted populations
Seamark et al. 2014, UK	To elicit FCGs views about the community support that made death at home possible	Qualitative design, grounded theory approach, retrospective	Maximum variation sampling, recruitment through GP practices. Bereaved FCGs (n=59)	Semi-structured interviews; cross-sectional thematic analysis	More positive experience for FCGs by: minimising number of carers involved, increasing/ensuring personal continuity, maximizing informational/organisational aspects of care	Retrospective approach. Data from a range of illness experiences. Highlights value of continuity of care (scrutinises out of ours care provision)
Sloss et al. 2012, Canada	To examine determinants of perceived spiritual and emotional support received by EoL ICGs	Substudy of large population based investigation of EoL experiences	Bereaved ICGs (n=621)	Structured telephone interviews, descriptive statistical analysis	Most ICGs not asked about their spiritual or emotional needs. Health professionals need to communicate offers for emotional support.	Low response rate, potential for recall bias, little interrogation of the concepts of spiritual or emotional support.
Terry et al. 2006, Australia	To describe the concerns of dying patients and bereaved ICGs about the problems faced as death approached.	Qualitative methods; regional hospice setting.	36 hospice patients; 18 bereaved ICGs	Interviews (patients); focus groups (carers); constant comparison approach to analysis	ICGs concerns included: accessing services/support; needing more help with practical issues; wanting more access to information about patient illness.	Small, regional sample. Focus primarily on cancer. Raises complex issues around privacy/information disclosure to ICGs against patients' wishes
Waldrop, 2006, USA	To explore and describe the interrelationship between informal and formal care in a terminal illness	Qualitative approach, exploratory descriptive study	64 families currently caring for someone receiving hospice care	Statistical analysis of records; in-depth interviews, thematic analysis, creation of genograms and ecomaps	Findings show quasi-formal and informal social support as link between informal and formal caregiving.	Only one interview per family, at one point in time. Value for FCGs of clear communication, information, guidance from formal caregivers

Author, year, country	Aims	Study setting/ design	Sample and sample size	Methods/analysis	Relevant findings	Weaknesses/ appraisal
Williams et al. 2008, USA	To examine the relationship between decedent and ICG characteristics and emotional and physical health of ICGs	Health outcome measures, clinical instruments	ICGs of 434 decedents (94% FCG; recently bereaved)	Stratified random sample; statistical analysis: linear mixed models	Informal social support linked to better physical health. Age, gender, education, financial burden and more care involvement associated with emotional strain	Cross-sectional study (cannot determine temporality or causality). Highlights various characteristics that increase and alleviate stress

Table 5: The impact of caregiving on informal caregivers

Author, year, country	Aims	Study setting/design	Sample and sample size	Methods/analysis	Relevant findings	Weaknesses/appraisal
Boquet et al. 2011, USA	To provide insight into the role of grandchildren as hospice ICGs	Qualitative case study approach, phenomenological approach	4 ICG grandchildren, part of a larger study on hospice ICGs	In-depth interviews/intervention workshops; thematic analysis	Emergent themes included experiencing: fatigue, stress, guilt, and loss of the "grandchild" identity.	Small sample. Moves beyond immediate FCG relationship.
Brazil et al. 2009, Canada	To determine gender differences in caregiver strain among spousal caregivers	Standardised measurement approach; cross-sectional community-based study	283 informal spousal caregivers currently caring for a terminally ill spouse	Structured telephone interviews; statistical analysis	Females had greater level of caregiving strain than males. Female spouse carers more likely to take on personal care tasks	Highlights gender differences in caregiving duties and strain/burden
Empeno et al. 2011, USA	To measure impact on ICG stress of a support project providing in-home support to ICGs of hospice patients	Single hospice setting; mixed methods; evaluation of pilot project	123 ICGs	Clinical measures and follow up interviews; Statistical analysis and thematic qual analysis	Additional service provision reduced ICG overload and stress	Single site/context. Highlights additional support for ICGs as beneficial for patients, ICGs and health services
Gaugler et al. 2008, USA	To examine association of employment status and gender with Cancer FCGs' reports of stress/well-being	Correlational, cross-sectional survey design	183 primary FCGs, recruitment through radiation oncology clinic	Structured interviews (in person or telephone); bivariate/multivariate statistical analysis	Working women more likely than working/non-working men to provide instrumental care. Working women more likely than men to report feelings of exhaustion/fatigue	Aimed at informing clinical interventions. Emphasises need to consider the context of cancer care when analysing the stress process
Hoefman et al. 2015, Australia	To investigate the Carer Experience Scale and the Care-related QoL instrument; to report ICG experiences	Palliative care services in Adelaide, SA; self-clinical QoL instrument measures	Patients receiving palliative care services and their carers (n=97)	Written questionnaires	Caregivers' and care recipients' health status and duration of caregiving were negatively associated with caring experiences	Focused primarily on testing the validity of clinical outcome instruments. Highlights some of the difficulties experienced by ICGs

Author, year, country	Aims	Study setting/design	Sample and sample size	Methods/analysis	Relevant findings	Weaknesses/appraisal
Kenny et al. 2010, Australia	To investigate associations between health-related QoL and ICG characteristics and caregiving situations	Cross-sectional study, Short Form-36 Health Survey tool	Purposive sample through 2 community palliative care services; 178 ICGs of palliative care patients	SF-36 survey; multiple regression analysis	Findings point to the need to recognise and adequately support ICGs to avoid potential health impairments	Cross-sectional (QoL/ health may fluctuate). Highlights risk of health problems and aspects of health that are impaired for ICGs in EoL contexts
McNamar a et al. 2010, Australia	To explore perceptions of health services support for EoL ICGs and the role of support in shaping FCG health	Mixed methods: administrative data and qualitative methods	1071 ICGs (primary data collection post-bereavement)	Administrative records data, semi-structured telephone interviews; statistical analysis, triangulation	Identifies a range of factors indicating which ICGs are more vulnerable; lack of support associated with non-preferred place of death	Retrospective study, recall bias potential. Highlights the need for support to targeted populations
Waldrop et al. 2005, USA	To understand how ICGs transition to end-stage caregiving and to illuminate its unique aspects using a stress process model	Qualitative approach	74 FCGs, recruitment through hospital admission records	In-depth interviews; constant comparison analysis	Transition to end-stage caregiving depends on understanding/ comprehension of terminality	Cross-sectional design. Recruitment only through hospital service. Need for professionals to provide information/ support to FCGs during final stages
Waldrop, 2006, USA	To explore ICG experiences of grief during terminal illness and bereavement	Mixed methods, hospice setting; exploratory descriptive phenomenological study	Purposive sample, 30 ICGs	Qualitative interviews (open coding), quantitative grief measurement instrument (statistical analysis)	ICG grief highly influenced by social context; relationships with family and friends	Small sample lacking diversity. Examines grief pre- and post-bereavement, highlights value of normalising grief experience/ responses
Williams et al. 2008, USA	To examine the relationship between decedent and ICG characteristics and emotional and physical health of ICGs	Health outcome measures, clinical instruments	ICGs of 434 decedents (94% FCG; recently bereaved)	Stratified random sample; statistical analysis: linear mixed models	Informal social support linked to better physical health. Age, gender, education, financial burden and more care involvement associated with emotional strain	Cross-sectional study (cannot determine temporality or causality). Highlights various characteristics that increase and alleviate stress

Table 6: Communication and preparedness for the end of life

Author, year, country	Aims	Study setting/design	Sample and sample size	Methods/analysis	Relevant findings	Weaknesses/appraisal
Burns et al. 2015, Australia	To analyse ICG characteristics reporting worse than expected caregiving experience	Annual random face-to-face cross sectional survey	1628 active EoL ICGs from South Australia	Retrospective, structured interviews; logistic regression analysis	Describes the factors associated with a worse than expected experience (gender, type of care, length of care)	Rigid measures, no exploration of expectations. Need for communication of expectations to improve experience
Cherlin et al. 2005, USA	To examine communication between FCGs and physicians about EoL care	Mixed methods	218 primary FCGs of patients with cancer	Structured survey (n=206), descriptive stats analysis; in-depth interviews (n=12), constant comparison analysis	Ineffective communication at EoL likely results from both physician's lack of discussion and FCGs difficulty hearing the news	Highlights problems and complexities of communication at EoL. Points to ambivalence for both FCGs and physicians in talking about bad news
Clarke et al. 2010, UK	To report on an approach to engage older members of the general public and ICGs in EoL discussions	Qualitative approach, listening events across the UK	Older people, ICGs, representatives from community groups (n=74)	Workshops (n=4), focus groups; framework analysis	Themes: communicating about end-of-life issues, factors that influence concerns about death/dying, advance care planning	Highlights variation in responses around needs at EoL, and people's willingness to talk about death/dying and find out more info about EoL care
Clayton et al. 2005, Australia	To explore views of terminally ill patients, caregivers, and PC HPs on informational needs for patients and ICGs	Qualitative approach	Patients (n=19), ICGs (n=24) recruited from Sydney-based PC services, health professionals (n=22)	Focus groups, interviews, qualitative thematic analysis	Patients and ICGs have very different informational needs. ICG informational needs often unmet by health professionals	Cross-sectional. Highlights complexities around HP management of info for patients /ICGs (issues around with-holding information, consent)
Donovan et al. 2011, Canada	To understand cultural factors in experiences of caregiving and bereavement	Longitudinal qualitative approach, Dutch reformed participants, Ontario	Purposive sample; 5 FCGs (15 interviews in total)	2-5 interviews with each participant over time; qualitative analysis/coding	3 themes emerged: cultural attitudes towards care, religious beliefs and coping, and culturally-informed care-seeking behaviours	Small sample size. Longitudinal emphasis allows for temporal analysis. Provides insight into the social, cultural and religious context of FCGs

Author, year, country	Aims	Study setting/design	Sample and sample size	Methods/analysis	Relevant findings	Weaknesses/appraisal
Dumont et al. 2008, Canada	To identify elements of FCG experience that influence (positively or negatively) adjustment to bereavement	Qualitative approach, informed by psychological theoretical models	Purposive sample, 18 primary FCGs, recruitment through larger quantitative study	Semi-structured interviews; content analysis	Bereavement shaped by illness symptoms, relational context, social /professional support, circumstances surrounding death	Advances literature on preventing bereavement complications, focus on early bereavement support and relational contexts
Foran Lewis, 2014, USA	To explore experiences of ICGs actively seeking formal EoL care, in particular hospice care, for a loved one with dementia	Qualitative phenomenological approach	Purposive sample, 14 ICGs actively seeking formal EoL care	In-depth interviews; thematic analysis of phenomena	Five themes emerged: setting the stage for heartbreak, reaching the boiling point, getting through the front lines, settling for less, and welcoming death	Small sample focused only on dementia. In-depth analysis of lived experience of managing informal and formal care. Highlights struggles of ICGs beyond cancer
Hebert et al. 2006, USA	To determine relationship between preparedness for death and mental health in bereaved ICGs of dementia patients	Prospective study of FCGs (dementia). Standardised assessment instrument and structured survey on 4 occasions over 18 months	222 bereaved FCGs from the Resources for Enhancing Alzheimer's Caregiver Health study, a multisite randomized ICG intervention trial	Descriptive analysis to characterise the sample; bivariate statistical analysis	Almost 25% of ICGs were not prepared for the death. These ICGs had more depression, anxiety, complicated grief symptoms.	Results suggest that interventions should be implemented prior to the death (rather than post-bereavement). Single question used to assess 'preparedness'; posed post-bereavement.
Holtslander et al. 2005, Canada	To explore the experience of hope for ICGs of palliative patients	Qualitative grounded theory approach, 2 Canadian cities	10 ICGs living with and caring for palliative patients	Semi-structured interviews, constant comparison and theoretical coding	Highlights value of hope (and the impact of eroding hope) for home-based ICGs in EoL settings	Small sample, cancer overrepresented. Examining experiences during EoL care captures the lived experience.
Hudson, 2006, UK	To explore FCG perceptions of relative's death and assess how well they were coping	Quantitative approach, part of a larger RCT	Bereaved FCGs (n=45) (advanced cancer focus)	Structured interviews, traumatic grief inventory measure; descriptive statistical analysis	Most FCGs were coping well. FCGs appreciated support provided by SPC services	Reveals important aspects of preparedness and benefits for FCGs in receiving information to prepare them for the future

Author, year, country	Aims	Study setting/design	Sample and sample size	Methods/analysis	Relevant findings	Weaknesses/appraisal
Seamark et al. 2014, UK	To elicit FCGs views about the community support that made death at home possible	Qualitative design, grounded theory approach, retrospective	Maximum variation sampling, recruitment through GP practices. Bereaved FCGs (n=59)	Semi-structured interviews; cross-sectional thematic analysis	More positive experience for FCGs by: minimising number of carers involved, increasing/ensuring personal continuity, maximizing informational/organisational aspects of care	Retrospective approach. Data from a range of illness experiences. Highlights value of continuity of care (scrutinises out of ours care provision)
Terry et al. 2006, Australia	To describe the concerns of dying patients and bereaved ICGs about the problems faced as death approached.	Qualitative methods; regional hospice setting.	36 hospice patients; 18 bereaved ICGs	Interviews (patients); focus groups (carers); constant comparison approach to analysis	ICGs concerns: accessing services/support; needing help with practical issues; wanting more information about patient illness	Small, regional sample. Focus primarily on cancer. Raises complex issues around privacy/information disclosure to ICGs against patients' wishes
Waldrop et al. 2005, USA	To understand how ICGs transition to end-stage caregiving and to illuminate its unique aspects using a stress process model	Qualitative approach	74 FCGs, recruitment through hospital admission records	In-depth interviews; constant comparison analysis	Transition to end-stage caregiving depends on understanding/comprehension of terminality	Cross-sectional design. Recruitment only through hospital service. Need for professionals to provide information/support to FCGs during final stages
Waldrop, 2006, USA	To explore and describe the interrelationship between informal and formal care in a terminal illness	Qualitative approach, exploratory descriptive study	64 families currently caring for someone receiving hospice care	Statistical analysis of records; in-depth interviews, thematic analysis, creation of genograms and ecomaps	Findings show quasi-formal and informal social support as link between informal and formal caregiving	Only one interview per family, at one point in time. Value for FCGs of clear communication, information, guidance from formal caregivers

Abbreviations:

ICG: Informal caregiver

FCG: Family caregiver

CG: Caregiver

EoL: End of life

Pall care/PC: Palliative care

SPC: Specialist palliative care

HP: Health professional