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## Part 2: Home-based family caregiving at the end of life: a comprehensive review of published qualitative research (1998–2008)

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### Abstract

Family caregivers are crucial for supporting home death. We reviewed published qualitative research on home-based family caregiving at end of life (1998–2008), synthesizing key findings and identifying gaps where additional research is needed. Multiple databases were searched and abstracts reviewed for a focus on family caregiving and palliative care; full articles were reviewed to extract data for this review. In total, 105 articles were included. Findings are presented in the following areas: the caregiving experience and contextual features; supporting family caregivers at end of life; caregiving roles and decision-making; and rewards, meaning and coping. We noted a lack of definitional clarity; a reliance on interview methods and descriptive, thematic analyses, and a relative lack of diversity of patient conditions. Research needs are identified in several areas, including the bereavement experience, caregiver ambivalence, access to services, caregiver meaning-making, and relational and contextual influences on family caregiving at end of life.

### Keywords

caregivers, home care services, palliative care, review, terminally ill

### Introduction

Family caregivers are crucial to health care systems, providing the majority of physical and emotional care for individuals with life-threatening and terminal illnesses, including those who wish to die at home.<sup>1–5</sup> Recognition of this contribution coincides with the conceptualization of the family caregiver as a ‘client’ or ‘pseudo-patient’ within palliative care philosophy, or as part of the unit of care.<sup>6</sup> In the context of government cost constraints, family caregivers are expected to take on more of the care once provided by nurses.<sup>7</sup>

However, demographic trends and social changes may affect their availability, as well as the need for such caregivers, particularly in home settings.<sup>8</sup>

Knowledge advancement in home-based family caregiving and end of life care has been hindered by a lack of research capacity.<sup>9–11</sup> In 2006, family caregiving was identified as a top international research priority in end of life care.<sup>12</sup> A review of the quantitative literature on family caregiving at end of life from 1998–2008<sup>13</sup> identified the potential for negative emotional, psychological and physical outcomes for caregivers, as well as for

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financial strain and occupational and social disruption. Factors associated with caregiver outcomes include patient socio-demographic and clinical characteristics, characteristics of the caregiving situation, and caregiver characteristics, including coping and appraisals.<sup>13</sup> However, the theoretical, causal, and explanatory mechanisms which lie behind such associations require greater attention. Qualitative research can make important contributions to understanding in this regard, as well as articulate the complexity and contextual embeddedness of family caregiving experiences, and assist in the development of empirically based conceptual and theoretical frameworks for research and practice. The purpose of this paper is to review published qualitative research on home-based family caregiving at end of life from 1998–2008, synthesizing key findings and identifying gaps where additional research is needed. Most of the last year of life is spent at home,<sup>14</sup> and primary carers play a key role in achieving home death.<sup>3,4</sup> By specifically targeting research on home-based family caregiving at end of life, we aim to identify distinguishing features of this experience and provide general yet context-specific background information to plan future interventions and inform policy development.

## Methods

In 2008–2009, we conducted a comprehensive review of empirical research on family caregiving at end of life, from January 1998 to August 2008, using a systematic approach which included several inclusion/exclusion criteria. A full description of the search strategies, review procedures and criteria are detailed in Part 1, with the exception that research included in the current review includes studies identified as qualitative and mixed method research with qualitative findings.<sup>13</sup> In brief, included articles addressed both family caregiving (i.e., not ‘family members’) and palliative/end of life situations. Only English language, empirical, peer-reviewed journal articles were included.

Only articles that clearly had a focus on home settings were included (i.e., not institutional care).<sup>13</sup> However, as with the quantitative research in this field,<sup>13</sup> many studies did not clearly specify the setting of care. In several studies, recruitment occurred in both inpatient and outpatient settings, but the number of participants in each setting was unspecified, nor were findings clearly differentiated between the settings.<sup>15–19</sup> These papers were included, as their findings were characterized as relevant to home-based care. Lastly, Sinding<sup>20</sup> and Sherwood et al.<sup>21</sup> did not specify a care setting, but were included based on an assessment of the relevance of the findings to understanding home-based family caregiving at end of life.

As discussed in Part 1,<sup>13</sup> methodological criteria were not used to exclude articles; our goal was a broad, comprehensive overview of published qualitative research in the field, as opposed to a systematic review, which focuses on generating a definitive answer to a narrowly defined research question.

The specific review procedures are documented in Part 1:<sup>13</sup> in brief, multiple databases were searched for relevant abstracts, which were reviewed to determine inclusion. Full articles for abstracts that remained after this first phase were retrieved and reviewed in-depth, to make final inclusion/exclusion decisions. Then, articles were reviewed to extract information regarding: research focus; caregiver status (bereaved or current); definition of family caregiver; methods of data collection; patient population; country of origin; theoretical or conceptual frameworks; and, for the present review, key or primary findings related to family caregiving experiences (commonly, this entails description of emergent qualitative themes). Key findings for all articles were synthesized by grouping and coding them thematically, with a focus on providing an overview of the primary types of findings and most common substantive topics generated in the field.

## Results

### Overview of articles

We identified 105 qualitative articles, including 18 mixed methods studies with qualitative findings. Table 1 summarizes some of the key methodological features of the articles. The largest percentage of studies ( $n = 51$ , 49%) focus on caregiving for cancer populations. An additional 38 (36%) include multiple patient populations or target hospice service recipients and, as such, are also likely to focus heavily on care for terminal cancer patients.

Forty-eight studies (46%) utilize samples of current caregivers; 31 (29%) use samples of bereaved caregivers; and 26 (25%) either include both bereaved and current caregivers or examine samples that transitioned from current to bereaved over the course of longitudinal study. As a general observation, the majority of samples tend to use convenience samples of volunteers, often recruited through formal service providers. While non-random samples are appropriate for qualitative research which does not aim for statistical generalizations to a population, ideally such samples would be selected purposively, guided by principles of theoretical saturation. Sample size was not coded for the qualitative studies reviewed here, acknowledging the differing purpose of qualitative methods, which seek in-depth exploration of phenomena and tend to gather greater amounts of information from a smaller number of participants.

**Table 1.** Descriptive summary of qualitative studies ( $n = 105$ )

Characteristic	$n$ (%)	References
<b>Patient conditions</b>		
Cancer	51 (49%)	20, 23–28, 30, 31, 38, 41–43, 45, 46, 48–50, 51, 54, 55, 59–62, 64, 67, 71, 72, 73, 76, 78, 80, 82, 83, 85–89, 91–93, 95, 97, 98, 101, 103, 118–121
Dementia	0	
HIV/AIDS	3 (3%)	29, 74, 75
Organ/system failure	6 (6%)	16, 18, 35, 37, 44, 70
Neurodegenerative	1 (1%)	34
Multiple patient populations	26 (25%)	15, 17, 21, 32, 33, 39, 47, 49, 52, 53, 56–58, 63, 65, 66, 77, 84, 90, 94, 102, 104, 122–125
Not specified, service recipients <sup>a</sup> (most often cancer)	12 (11%)	19, 22, 36, 40, 79, 81, 96, 106, 126–129
Not specified or not applicable	6 (6%)	68, 69, 99, 100, 105, 130
Total	105	
<b>Caregiver status</b>		
Bereaved	31 (29%)	17, 20, 21, 28, 30, 38, 41, 45, 51, 54, 58, 60, 63, 66, 68, 70, 74, 76, 80–82, 87, 89, 90, 95, 101, 102, 105, 118, 130, 131
Current	48 (46%)	15, 16, 18, 24, 27, 29, 31–33, 35, 39, 42–44, 46, 48, 49, 50, 52, 55, 56, 61, 62, 64, 65, 71, 73, 75, 79, 84–86, 88, 91, 94, 96, 97, 99, 103, 106, 115, 120, 121, 123, 124, 132–134
Both/transition	26 (25%)	19, 22, 23, 25, 26, 34, 36, 37, 40, 47, 53, 57, 59, 67, 69, 72, 77, 78, 92, 93, 98, 100, 104, 119, 122, 125
Total	105 (100%)	
<b>Data collection<sup>b</sup></b>		
In-person interviews	93 (74%)	15, 17–20, 22–37, 40–46, 48–66, 68–79, 82–104, 106, 118, 120–125, 131–134
Telephone interviews	7 (6%)	15, 39, 48, 69, 97, 121, 130
Self-administered or mailed	10 (8%)	21, 25, 26, 38, 47, 65, 81, 83, 88, 119
Other or not described	15 (12%)	36, 37, 47, 50, 63, 65, 67, 70, 71, 75, 77, 80, 89, 105, 130
Total	125 (100%)	
<b>Country<sup>c</sup></b>		
UK	35 (33%)	16–18, 22, 31, 37, 39, 41, 44, 51–54, 65, 71, 73, 76, 78, 80, 81, 89–93, 96, 97, 102, 106, 120, 123, 124, 131, 133, 134
USA	23 (22%)	21, 23, 32, 35, 40, 43, 48, 49, 59, 61, 68–70, 74, 79, 94, 95, 98, 104, 118, 121, 125, 130
Australia	17 (16%)	15, 19, 25, 26, 33, 34, 36, 42, 47, 50, 55, 72, 83, 99, 103, 105, 119
Canada	17 (16%)	20, 27, 29, 30, 45, 46, 56, 57, 60, 63, 66, 67, 77, 82, 84, 101, 122
Europe	10 (9%)	24, 38, 58, 62, 64, 85, 86, 88, 100, 132
Africa	1 (1%)	73
Asia	3 (3%)	28, 75, 87
Total	105 (100%)	

<sup>a</sup>These are most likely to be cancer as they were recruited clients from hospice or palliative care services; however, the author(s) did not specify.

<sup>b</sup>Studies with more than one method of data collection were coded for each method (i.e., more than once): as such, cell totals for method of data collection total more than 105. Some 20 articles (19%) include more than one points of data collection.

<sup>c</sup>Murray et al.<sup>73</sup> collected data in both the UK and Africa and was coded twice. As such, cell totals for country total 106.

Open-ended interviews and focus groups were the dominant mode of data collection (93 studies; 89%). Most ( $n = 35$ ; 33%) of the identified qualitative studies originated in the UK; 23 (22%) from the USA; 17 (16%) from Australia; and 17 (16%) from Canada.

Findings in this respect may have been influenced by the English-language criteria for inclusion.

We further discovered that ‘family caregiver’ is either not defined, or only minimally defined, in the overwhelming majority ( $n = 85$ ; 81%) of studies.

Definitions extended little beyond the criteria that family caregivers be self-identified or identified by patients or hospice or medical staff as the main family caregiver. Other existing definitions add a few additional specifications, such that the individual is unpaid or providing the majority of care/primary role or responsibility, and providing help or support to a family member (in some cases, friends/neighbours). Rarely is care itself defined, except as in 'regularly providing one or a combination of practical, emotional, or physical care'.<sup>22,23</sup> Time periods are also rarely defined, except for example, as in: 'providing the majority of . . . care . . . throughout his/her illness'.<sup>23</sup>

While not coded explicitly, we also observed that the qualitative data in the articles we reviewed typically were analysed using thematic or content analyses or various related strategies drawn from grounded theory methodology (constant comparison, theoretical coding). Most often, very little analytic detail is provided in methodological descriptions.

### Synthesis of findings

We provide an overview of key findings from the qualitative literature, which were grouped and coded thematically.

**The caregiving experience and contextual features.** Qualitative research can generate detailed, nuanced, 'grounded', and contextualized understandings of individual experiences. While the detail included in qualitative findings is difficult to convey in summary fashion, we present several common (though by no means universal) aspects of caregiving experience at end of life, identified in the literature we reviewed.

In general, the reviewed literature described home-based family caregiving at end of life as involving intense, conflicting, negative and/or difficult emotions,<sup>23–33</sup> such as fear and dread,<sup>18,28,34,35</sup> anger and disillusionment,<sup>29</sup> guilt and regret,<sup>18,28,36</sup> anxiety,<sup>18,37–39</sup> grief,<sup>34,40</sup> helplessness,<sup>37,41</sup> and hopelessness.<sup>28</sup> Contributing to these strong, often negative emotions are the impact of diagnoses,<sup>26</sup> patient deterioration and suffering,<sup>25,34,42</sup> and cumulative losses over time.<sup>43,44</sup> For instance, the nature of the patient's illness and prognosis can facilitate or impede family caregiver coping.<sup>37,45,46</sup>

Providing care at home can itself be a source of stress,<sup>32</sup> which in palliative situations is compounded by awareness of a terminal diagnosis. Home-based caregiving can be physically demanding and this, alongside emotional experiences, can negatively impact physical health.<sup>16,23,26,27,33,38,41,47</sup> Sleep disturbances are documented,<sup>40,48</sup> as are self-care difficulties,<sup>35</sup> although some actively try to maintain stamina in order to

continue to provide care:<sup>49</sup> respite can also help in this regard.<sup>30</sup>

Being involved in care, and feeling able to effectively provide quality care, is suggested to enhance family caregiver coping.<sup>24</sup> However, qualitative literature documents considerable challenges faced by family caregivers providing practical care to dying individuals, including personal and physical care and symptom management; caregivers have needs for support and information in this regard.<sup>17,25,33,49–53</sup> Caregivers' lack of preparation, knowledge and/or ability is a common finding, especially regarding symptom, pain, and medication management,<sup>31,37,42,47,48,54–56</sup> as well as technological tasks.<sup>35</sup> Feelings of being unprepared are exacerbated where caregivers lack previous experience with dying or caregiving, or where there is an absence of sufficient guidance, including from formal service providers.<sup>19,24,48</sup> Qualitative findings illuminate a potential connection between this lack of preparedness and caregiver reports of fear, anxiety, stress, and feelings of insufficiency and uncertainty about their abilities.<sup>24,38,41,55,57,58</sup> Caregivers' sense of responsibility can further exacerbate anxiety,<sup>54</sup> as caregivers may sense their ability to provide adequate care is key to a home death.

Family caregivers have needs not only for information about the practical aspects of care at end of life, but also for more general information about the patient's disease.<sup>24,53</sup> For instance, Harding et al.<sup>16</sup> report that family caregivers of coronary heart failure patients tended to have poor understanding of the disease. However, as Waldrop et al.<sup>32</sup> note, absorbing disease-related information involves being able to comprehend and/or accept the terminal diagnosis; Cherlin et al.<sup>59</sup> describe caregiver difficulties in regards to 'bad news'. Ultimately, information preferences vary between individual caregivers, though Clayton et al.<sup>15,50</sup> emphasize the overall importance of consistency of information and clarifying understanding and communication preferences.

The experience of bereavement among family caregivers who provide palliative care at home is described as devastating and requiring follow up and/or support from formal services.<sup>56</sup> Grbich et al.<sup>26</sup> note that even though the intensity of caring activities stop, painful emotions continue and can worsen in bereavement. Waldrop<sup>40</sup> observes that overall distress, anxiety, and hostility decreased, but loneliness, sadness, and tears increased. While there may be some positive outcomes such as an end to intense caregiving or a sense of relief at the cessation of patient suffering, Koop and Strang<sup>60</sup> argue that positive outcomes are less evident than negative impacts, which can include being haunted by images of suffering and feeling remorse at not having reduced suffering.

Features of the social and support context can inform the individual experiences of family caregivers. Family care for dying individuals at home is described as a 'cocoonlike' experience<sup>30</sup> that appears separate from everyday life; caregivers often have difficulties with social isolation.<sup>17,35–37,41,56</sup> Social isolation may stem from caregivers' reluctance to leave home,<sup>24</sup> a lack of caregiver time and awkwardness talking about the illness,<sup>57</sup> as well as others' unwillingness to be involved;<sup>57</sup> social isolation may also be exacerbated by a lack of formal supports.<sup>47</sup>

Caring for a dying family member at home tends to involve considerable lifestyle changes and disruption,<sup>49,61</sup> yet continuing previous activities may facilitate coping.<sup>62</sup> There is recurring emphasis on caregivers' desire for and struggle to maintain a sense of a normal life for the patient and family, including normal routine.<sup>34,35,61,63,64</sup> For instance, formal services (such as respite) may provide an opportunity for the caregiver to experience 'normal life',<sup>39</sup> adding a 'semblance of normality' to an uncertain situation<sup>65</sup> and to the life of the dying person.<sup>30</sup> The desire for normalcy can be seen as stemming from the perception that family caregiving at end of life entails a disruption of, or even an end to, normal life and its patterns.<sup>58,66</sup>

Caring for dying individuals at home also creates and involves significant time investments and time pressures that are especially salient for family caregivers who face competing roles and obligations in their lives.<sup>27,32,33,37,39,41,47,56,57,67</sup> Caregiving at home can have particularly negative impacts on finances and employment,<sup>25,27,32,33,35,47,52,53,56,57,67,68</sup> thereby generating additional stressors.

Qualitative research has also sought to delineate how the caregiving experience can change over time,<sup>28,31,32,58,66,69</sup> as well as explore complex personal and/or existential features of the experience, such as how it can transform fear of death to awareness of death<sup>70</sup> and how it highlights a tension between dependence and independence.<sup>71</sup> Some studies also address the relational context of caregiving: for instance, dying persons may continue to care for and about caregivers and other family members;<sup>41,69</sup> caregivers may view care as a natural extension of the family relationship or marriage partnership,<sup>27,67</sup> and some must negotiate with the care recipient to accept formal services<sup>57</sup> and deal with family conflicts.<sup>35,42</sup> Family caregivers have identified that when they had a good relationship with the dying care recipient<sup>46,72</sup> or other family members,<sup>45</sup> and when the patient recognized and appreciated their caregiving contribution,<sup>46</sup> they were better able to cope and had more positive experiences.

Some qualitative research also advances an understanding of home-based family caregiving at end of life

as embedded within broader cultural, social, political, and economic contexts that structure the experience and its interpretations and meanings.<sup>17,20,28,29,41,56,66,72–78</sup> For example, Somerville<sup>41</sup> emphasizes how care demands among families of Bangladeshi origin living in the UK are exacerbated by communication barriers, isolation and difficulties regarding housing and immigration visas. Other studies explicate the challenges of providing family care at end of life in the context of the stigmatization of HIV/AIDS.<sup>29</sup> Rhodes and Shaw<sup>17</sup> illustrate difficulties with access to formal services in rural areas. Others demonstrate how care decisions and experiences can be influenced by culturally and socially normative ideals of family care and dying at home<sup>77,78</sup> and reforms to and erosions of formal public care services.<sup>17,20,56,66,77</sup> Research into the contextual features of family caregiving at end of life tends to be embedded in theoretical perspectives that are feminist, geographic, sociological, and anthropological in nature, as opposed to, for instance, more traditional psychological frameworks.

Several studies that we reviewed endeavoured to synthesize various features and processes involved in family caregiving experiences into an emergent, overarching conceptualization or theory. For instance, some conceptualize family caregiving at the end of life itself as fundamentally uncertain/ambiguous, in part because of the unpredictability of the trajectory.<sup>31,49,64</sup> Others identify a core concept of powerlessness or helplessness, which can involve caregivers' perceptions of patient suffering and deterioration, feelings of inability to relieve patient pain and discomfort, and related feelings of guilt, anger, loneliness, and social isolation.<sup>38</sup> A related concept of insufficiency is developed by Broback and Bertero,<sup>24</sup> that encompasses a lack of knowledge about patient care as well as broader feelings of isolation. Read and Wuest<sup>66</sup> propose that caregiving by adult daughters can best be understood with reference to a concept of turmoil (i.e., emotional, relational, and daily life upheaval, as well as societal upheaval in the form of cutbacks to formal services). Further, Proot et al.<sup>62</sup> develop a framework of vulnerability representing caregivers' risk of fatigue and burnout that they theorize is influenced by various burdens, and Read and Wuest<sup>66</sup> develop a theory of 'relinquishing' focused on caregivers' strategies to monitor parental needs, maintain control, navigate formal systems, prepare for loss, and cope with bereavement. In another study, the experience of providing care to a dying family member is conceptualized as 'balancing caregiving activities and disruptions while dealing positively with daily demands and personal impact'.<sup>61</sup> Lastly, Mok et al.<sup>28</sup> theorize family caregiving at the end of life as a process involving the following transitional phases: holding onto hope, taking

care, preparing for death, and adjusting to another phase of life.

**Supporting family caregivers providing palliative care.** Qualitative research on home-based family caregiving at the end of life emphasizes the importance of informal and formal support in various areas (e.g. instrumental, emotional, informational) for those providing such care.<sup>17,19,23,32,62,72,79,80</sup> Problems associated with a lack of support<sup>42,62</sup> or unsupportive interactions<sup>21,27,41</sup> are also detailed. Formal and informal support can facilitate coping.<sup>34,45,46,68,81,82</sup> In this respect, Stajduhar and Davies<sup>29</sup> propose that the structure of the health care and social service systems, the accessibility of services, and the nature of support can influence the nature of caregiver experiences. Caregivers emphasize that trusting relationships, support networks, and sharing caregiving tasks contribute to security,<sup>30,46,83</sup> hope,<sup>84</sup> reassurance,<sup>85</sup> an enhanced 'semblance of normality' and comfort,<sup>65</sup> a sense of 'togetherness' with others and trust,<sup>85,86</sup> and manageability.<sup>86</sup> Support can also mitigate anxiety, stress and uncertainty,<sup>24,57,80</sup> vulnerability,<sup>51,62</sup> and feelings of abandonment or isolation.<sup>51,86,87</sup>

In light of these findings and identified support needs, some studies we reviewed described caregiver experiences with formal services. With perhaps the exception of Milberg and Strang,<sup>88</sup> who develop a conceptual framework of experiences with palliative home care staff, this research most often focuses on caregiver satisfaction. Caregivers tend to express appreciation and satisfaction when health care providers, services and/or equipment are: adequate and competent;<sup>49,56,88</sup> flexible;<sup>56,89</sup> coordinated and organized;<sup>23,25,27,52,53,56</sup> continuous/consistent;<sup>27,37,53,88</sup> accessible and available;<sup>34,51,52,88,89,90-93</sup> and have open and adequate and appropriate communication and caregiver involvement.<sup>23,25,27,41,52,53,89,94</sup> Further, caregivers appreciate information and advice from providers,<sup>16,25,87,95</sup> being connected with other services,<sup>90</sup> and the demonstration by providers of positive, caring attitudes that suggest 'caring about'<sup>23,90,93,94</sup> as well as 'caring for' by providing direct care and support.<sup>88,90,91,93,96</sup> Family caregivers generally desire and enjoy good relationships and/or partnerships with health care providers.<sup>37,44,49,87,89,90</sup> The conceptualization of 'good' relationships remains to be more fully explored and can include, for instance, personal liking for, rapport and familiarity with, and trust in providers<sup>90</sup>; being included as a team member in the process of care<sup>49</sup>; and/or when providers become 'trusted confidants' who view the client as a 'friend' and are committed and engaged in the relationship.<sup>84</sup> Lastly, some findings emphasize a need to recognize caregiver expertise and ability<sup>37</sup> and affirm their self-worth.<sup>84</sup>

While we provided a general overview of perceptions of and satisfaction with formal services in the qualitative literature on family caregiving at end of life, some have argued that given individual variation in preferences and expectations, the best approach is to individualize services for caregivers depending on their needs,<sup>72</sup> providing 'personal touches'<sup>93</sup> and personalized care.

**Barriers to support provision.** While caregivers often want to be recognized in their role and perceived as a separate person (the patient usually being the focus of care),<sup>24</sup> and to be supported and provided with information regarding patient care, many express reluctance with or have difficulties acknowledging and disclosing their own needs to formal providers and asking for help.<sup>1,35,54,57,81</sup> Harding and Higginson<sup>22</sup> describe this phenomenon with reference to the concept of ambivalence: caregivers in their study were often ambivalent with regard to their own needs, acknowledging they existed but being reluctant to self-identify as a caregiver in need of support. This phenomenon has been linked to concerns about the legitimacy of needs,<sup>97</sup> not wanting to bother formal providers,<sup>97</sup> negative perceptions about and previous experiences with formal services,<sup>97</sup> and a desire to keep the focus of care on the patient.<sup>57</sup>

As such, the qualitative literature on family caregiving at end of life provides insight into the complexity of service utilization. Other than caregiver ambivalence and reluctance to articulate their own needs, documented qualitative explanations for *not* using formal services include: personality;<sup>54</sup> including a desire for self-reliance;<sup>92</sup> coping style, such as coping through escape;<sup>22,54</sup> resistance from the care recipient;<sup>56,57</sup> difficulties with access including geographic location, negotiating bureaucracy,<sup>56,97,98,99</sup> a lack of information about services/contact persons,<sup>56,97,100</sup> and lack of time;<sup>98</sup> negative previous experiences with and perceptions of the quality of formal services;<sup>56,97,98</sup> discomfort with particular features (e.g. not wanting to leave the care recipient alone, for respite;<sup>22,30</sup> discomfort talking to others, for bereavement services;<sup>98</sup> fear of strangers);<sup>29</sup> sense of responsibility and duty to care;<sup>41</sup> not perceiving a need<sup>98</sup> or having other support available;<sup>98</sup> culture and/or beliefs about family care;<sup>54,99,100</sup> and social pressure to provide home care.<sup>100</sup>

**The caregiving role and decision-making.** Studies often refer to the term 'caregiving role', although as in much of the quantitative literature in this area,<sup>13</sup> this is not clearly defined. Most often the concept is used in descriptions of expected caregiver responsibilities, the adoption of, transition into and adjustment to the new role (and into dual roles of family member and caregiver),<sup>24,64</sup> and the trajectory or evolution of the

role or career.<sup>69,101</sup> Sherwood et al.<sup>21</sup> observe that while caregivers faced challenges related to role overload and conflict, role ambiguity (unclear feelings or expectations) was not apparent. Other studies detail caregivers' expectations and goals, including advocating on the patient's behalf,<sup>101</sup> or providing technological care.<sup>35</sup> Other caregivers define their role in terms of presence and psychological support;<sup>43</sup> friend and neighbour caregivers and non-spousal caregivers may be less comfortable with decision-making roles.<sup>67,101,102</sup> While caregivers tend to have varying preferences in terms of the level and scope of their involvement, for some caregivers, a lack of participation and involvement can result in feelings of insufficiency and frustration.<sup>24</sup>

Several articles examine decisions and motivations to adopt and/or continue in the family caregiving role. Such decisions have been described as a 'loving' or 'conscious' choice<sup>56,79</sup> in some research, but as absent of choice<sup>20,37,64,74</sup> in others. Aranda and Peerson<sup>103</sup> describe family member decisions to provide palliative care at home as involving a more complex blend of choice, desire, obligation, and constraining factors. There may also be individual variation: some family caregivers interviewed by Stajduhar<sup>77</sup> and Stajduhar and Davies<sup>63</sup> described 'snap' (e.g., automatic) decisions; others described indifferent or reluctant decisions (with little sense of choice), and yet others described how they negotiated decisions with the dying person (and had more sense of choice). Conceptualizations and theories of family decisions to provide palliative care at home are also evident in the literature and include the above-mentioned work by Stajduhar,<sup>77</sup> and Turner and colleagues,<sup>104</sup> who examine choices among African American family caregivers, drawing on a framework that emphasizes a wide range of influencing factors that vary cross-culturally, including trust in health care providers and the health care system more generally.

Various factors are identified qualitatively as influencing family caregiver decisions to provide end of life care at home, including: caregiver capacity and structural circumstances influencing capacity,<sup>17,78,103</sup> patient desires and choice,<sup>51,63,64,77</sup> the relationship with the care recipient<sup>103</sup> and love;<sup>56,93</sup> a lack of alternatives;<sup>56,58</sup> and more broadly, the nature and availability of formal health care services.<sup>20,64,77</sup> Caregivers also refer to their personal motivations to return past care and support,<sup>17</sup> maintain a 'normal family life',<sup>63</sup> preserve care recipient dignity,<sup>104</sup> promote family autonomy,<sup>101</sup> and, often, to avoid poor quality or uncoordinated formal services and institutions.<sup>51,56,63,64,77,78</sup>

More broadly, collective norms and values originating in families, cultures, and religious traditions,<sup>71</sup> including those concerning kinship and death<sup>20</sup> and dying at home,<sup>77</sup> have also been suggested as

motivating individual decisions to provide palliative care at home to a family member. Likewise, individual beliefs about, attitudes towards, and previous exposure to death and dying may also play a role,<sup>64,78</sup> and Sinding<sup>20</sup> documents how a sense of an imperative to provide care can be generated through knowledge of a terminal diagnosis in a family member.

In other qualitative studies, feelings of responsibility, duty and commitment are associated with decisions to provide home-based care for dying family members.<sup>20,24,28,31,41,51,56,64,74,93</sup> Further, Johnson and Bourgeois<sup>105</sup> suggest that caregiving demonstrates commitment; and mothers in a study by Nelms<sup>74</sup> also emphasized their commitment to care as the essence of 'mothering'.

**Rewards, meaning, and coping.** While there are a variety of factors motivating family caregivers to provide care to dying family members, the experience has been described as stressful,<sup>17,24,79,106</sup> burdensome,<sup>44,52,68</sup> and involving hardship and pressure.<sup>36</sup> However, some family caregivers describe aspects of their experiences as positive or rewarding, often simultaneously with talk of challenges and problems.<sup>33,42,55,58,95</sup> Identified positive features include: a sense of pride, esteem, and mastery as a caregiver;<sup>26,27,29,35,42,47,60</sup> a sense of normalcy;<sup>35</sup> being able to demonstrate love and fulfill reciprocity;<sup>25,60</sup> satisfaction and sense of accomplishment;<sup>60,81</sup> sense of relief and ability to be with and help the patient;<sup>35,60,68</sup> life-enriching experiences;<sup>77,29</sup> closer relationships;<sup>27,42,47,60,99</sup> a sense that it is important for the patient and therefore meaningful;<sup>28,33</sup> inner peace;<sup>28</sup> broader transformations in outlook such as renewed appreciation for life;<sup>28,68</sup> transforming fear of death to awareness of death;<sup>70</sup> reaching out to others;<sup>68</sup> and changes in/clarity of self-identity/personal growth.<sup>60,70</sup>

The positive features of family caregiving at the end of life described in qualitative research help provide a more comprehensive and nuanced description of the experience; however, these findings can be interpreted as reflecting processes of meaning-making and caregiver coping. For example, some of the work we reviewed proposed that aspects such as satisfaction with one's own abilities as a caregiver can be a coping strategy<sup>106</sup> that decreases caregiver vulnerability<sup>62</sup> and represents an inner dimension of the meaning of support.<sup>85</sup> Further, feelings of commitment can serve as a source of meaning, comfort and strength, accomplishment, and satisfaction for caregivers, contingent on their particular interpretations.<sup>56,68</sup>

As such, it has been suggested that some caregivers may actively use positive interpretations and the identification of rewards as a meaning-based coping



resource.<sup>42</sup> Strang and Koop<sup>82</sup> posit that bereaved caregivers' coping is 'grounded in the meaning associated with their experiences'. Others emphasize the importance, for caregivers, of finding meaning<sup>61</sup> and maintaining a congruent inner reality,<sup>86</sup> or using faith and religious-based beliefs to help cope.<sup>32,43,84,104</sup> For instance, Nilmanat and Street<sup>75</sup> describe how Buddhist Thai family caregivers mobilized religious resources and the concept of karma to make sense of and provide meaning to their situations, providing a sense of strength and comfort.

As well as identifying positive features of and meanings in caregiving, additional caregiver coping strategies documented in the literature we reviewed include: maintaining hope and a positive outlook on life;<sup>61,62,72,84</sup> 'living one day at a time' or 'in the moment';<sup>46,72,84</sup> focusing on simply 'getting on with it';<sup>34,46,84</sup> avoidance;<sup>79</sup> and maintaining control and setting limits.<sup>62</sup> Factors suggested in qualitative research as potentially impeding coping among family members providing end of life care include the stressors or challenges documented earlier in this review. Factors facilitating coping include the specific strategies documented above, as well as caregiver characteristics, and features that provide support and make caregiving easier (e.g., patient or disease characteristics, contextual features), enabling the caregiver to continue in their role.

## Discussion

### *Methodological challenges*

We have reported a broad, comprehensive overview of the state of the recent contributions of qualitative research to the understanding of home-based family caregiving at end of life. While methodological criteria were not applied to assess individual papers and this could be viewed as a limitation, we observed several methodological challenges in the body of literature as a whole.

The largest percentage of studies we reviewed (particularly if one also considers the 'not specified, service recipients' category in Table 1) focus on family members providing palliative care for cancer patients – most likely reflecting difficulties in prognostication for non-malignant conditions. Often, however, the patient condition was not specified, or the sample comprised persons with a number of different diagnoses. Given the importance of describing a diversity and wide range of types of experiences in qualitative research, future studies should focus on (and specify) caregiving for more diverse patient conditions, settings and types of caregivers, as well as caregivers who are receiving services and those who are not.

We faced challenges in extricating family caregiver-specific findings from articles with multiple samples, where findings for patients and caregivers (and sometimes health professionals) were integrated together in the results section. The distinctive nature of the caregiver experiences in these studies tends to be lost: 'by aggregating the family, the needs of individual caregivers may be neglected and problems specific to the caregiver or arising from the caregiver-patient relationship may be ignored'.<sup>65</sup>

While the views of both bereaved and current caregivers are important, caution is needed when bereaved samples are used for retrospective accounts of caregiving experiences. For instance, bereaved caregivers may be more likely to report positive features of caregiving<sup>23</sup> and to evaluate institutional services positively.<sup>107</sup> In contrast to retrospective accounts, the experience of bereavement itself among family caregivers who provided end of life care, has not been extensively studied using qualitative methods: contextual features of bereavement, for instance, have not been fully explored.

Further, and paralleling similar findings in the quantitative literature (Part 1),<sup>13</sup> there was a distinct inconsistency in and/or lack of reported definitions (notably, of 'family caregiver' and 'palliative' or 'end of life'). This challenges the ability to compare and synthesize the findings of different studies and highlights a need for definitional development and consensus-building.<sup>13</sup>

Interviews were the dominant mode of data collection in the studies we reviewed, consistent with those who argue that contemporary qualitative research is most often equated with interviewing<sup>108</sup> (as opposed to, for example, observational research or textual analysis). However, we raise cautions about the reliance on interviews in the study of family caregiving, as participant talk is not an unmediated representation of caregiving experiences, but instead, reflects broader social and cultural ideals and caregivers' active attempts to cope by constructing the meaning of their experience.<sup>109</sup>

Thematic or content analyses were the most commonly cited analytic methods, as well as methods drawn from grounded theory approaches (constant comparison, theoretical coding). Grounded theory was the dominant methodology, as opposed to, for instance, interpretive inquiry and narrative methods, ethnography, phenomenology, or discourse analysis. The qualitative findings with regards to family caregiving at the end of life may therefore be limited by the lack of diversity of methodological approaches.

Perhaps in part due to the reliance on thematic analyses, findings from the qualitative literature tend to be conceptually under-developed descriptive lists, much as documented by Sandelowski and Barroso<sup>110</sup> who note

a general dearth, in qualitative research, of researcher interpretation and nuanced descriptions. Few of the studies we reviewed conducted higher-level qualitative analyses, which might include, for example: applying concepts from existing literature to analyse or reframe study findings;<sup>110</sup> testing the ‘fit’ between the data and existing theories, in order to refine existing theories;<sup>111</sup> offering ‘a coherent model of some phenomenon, or a single thesis or line or argument that addresses causality or essence’;<sup>110</sup> theorizing by moving beyond coding to ask the general analytic question ‘what is happening here?’;<sup>112</sup> integrating concepts ‘into a linked and logical portrayal’;<sup>113</sup> and exploring how an experience or causal pathway ‘varies depending on individuality and context’.<sup>113</sup> Reliance on coding and thematic categorization may result in an over-abundance of de-contextualization, as opposed to understanding individual experiences and interpretations in the context of life histories, family dynamics, geographies, and social positions.

Caution is needed in the generalization of the descriptive findings in the studies we reviewed (given small sample sizes and non-representativeness). However, Leininger<sup>112</sup> favours the alternative concept of ‘transferability’ for qualitative research which ‘focuses on general similarities of findings under similar environmental conditions, contexts or circumstances’.

The findings from these studies cannot all be characterized as grounded, open-ended, comprehensive understandings of caregiving experiences, as many studies are guided by research and interview questions which target very particular aspects of caregiving. Lastly, whereas one of the strengths of qualitative research is that it can assist in understanding experiential diversity and individual variation, most studies we reviewed provide general summaries of the most common themes and risk obscuring particularities. The challenge for future qualitative research in family caregiving at end of life is to generate information that is useful for policy-makers and practitioners while remaining true to the richness and complexity of individual, contextualized experiences.

### *Qualitative literature synthesis*

While caution is needed due to the methodological and conceptual limitations of this body of literature, it is possible to draw some overall conclusions. Research findings suggest that home-based family caregiving at the end of life involves intense, often negative, and at times conflicting emotions and stress. While this can stem from the impending loss of and watching the suffering of the patient, providing care can also be a source of stress, particularly when there is uncertainty about what to do or a lack of support and information.

Caregivers often report feeling unprepared for their role and consequently uncertain and anxious, particularly when they feel responsible for providing care and a home death. In fact, the caregiving experience at end of life has been conceptualized as involving uncertainty, powerlessness, insufficiency, vulnerability, and turmoil. Further research is needed both to explore more fully why these caregivers feel unprepared and how best to support them through interventions and programmes.

Family members providing palliative care at home have also described a number of additional stressors, including declines in physical health, social isolation, lifestyle changes and disruptions, time pressures, and negative impacts on finances and employment. The impact of time, financial, and employment pressures on individual caregivers may vary depending, for instance, on their socio-economic position and broader government and workplace policies. Caregivers’ desire to maintain a sense of normalcy, as well as relational issues they face in providing care, have also been highlighted, but require more attention. Further, more research is also needed that extends beyond the individual level to examine how home-based family caregiving at the end of life is structured within broader cultural, social, normative, geographic, political, and economic contexts. Such research should also be undertaken using clearly defined terms to specify the samples and circumstances of care as argued in our previous paper.<sup>13</sup>

Qualitative research on home-based family caregiving at the end of life emphasizes the importance of informal and formal support as promoting, for example, coping, security and reassurance, and manageability. Findings document core features of caregiver satisfaction with formal services and providers, yet interpretations tend to remain relatively underdeveloped and atheoretical. Many caregivers however express a wide range of reasons why they do not utilize formal service support, which demonstrate the complexity of supporting family caregivers. This includes, for example, reluctance or ambivalence regarding asking for help from formal providers, particularly with regard to their own needs. As noted elsewhere,<sup>114</sup> this is one of the dilemmas involved in trying to assist those who occupy the ‘dual roles’ of family member and caregiver.<sup>115</sup> More research is needed to fully explicate this phenomenon of ambivalence and the dynamics of conflict and/or reconciliation between these dual roles. Studies explicitly exploring service accessibility, from a qualitative perspective, are also rare.

There has been considerable qualitative interest in the decision to adopt the caregiving role and/or motivations for continuing in the role. Findings are mixed, but suggest such decisions and commitments reflect a complex blend of voluntary and obligatory motivations

and a wide variety of considerations, some of which are linked at the broader level to features influencing caregiver capacity and the availability or lack of alternatives for care. Further research could also focus to a greater extent on describing the processes in which role expectations and responsibilities are negotiated in interactions (in families and with providers) over time, as well as how movement into, through, and out of the caregiving role is connected to self identity. Further, while a variety of factors are identified as potentially influencing decisions to provide palliative care at home, future research should consider an alternative, more interpretive perspective that views post-hoc accounts as socially influenced justifications for decisions.

Some family caregivers describe aspects of their experiences as positive or rewarding in some way (such as a sense of accomplishment). Such descriptions provide insight into how caregivers cope by actively creating a sense of meaning in their role (e.g., one of a variety of coping strategies) and suggest that positive accounts should not always be interpreted as directly equating with positive outcomes. Indeed, we suggest that the process and outcome of coping may be difficult to distinguish and that further attention should be directed to an understanding of the process through which individuals construct and create positive interpretations of caregiving.<sup>111</sup> The importance of interpretation and meaning-creation (in the form of subjective appraisals) is perhaps most obviously acknowledged in theoretical models of caregiver stress and coping models such as that of Lazarus and Folkman,<sup>116,117</sup> often employed in quantitative research on family caregiving at the end of life.<sup>13</sup> This is not to downplay the importance of objective and contextual features of the caregiving experience that can create particular challenges, but to highlight the need, at the qualitative level, to examine the processes through which family caregivers create meaning, as well as the broader social norms and ideals they draw upon in this regard.

In conclusion, the ultimate purpose of this comprehensive review was to identify important gaps in the existing literature and areas for future conceptual and empirical work. By effectively enhancing our knowledge base in family caregiving at the end of life through targeted work in these areas, we can contribute to the development of recommendations for health care policies, services, and interventions to support family caregivers in their efforts to assist the terminally ill at home.

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