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Abstract

The changing context of palliative care over the last decade highlights the importance of recent research on home-based family caregiving at the end of life. This article reports on a comprehensive review of quantitative research (1998–2008) in this area, utilizing a systematic approach targeting studies on family caregivers, home settings, and an identified palliative phase of care ($n = 129$). Methodological challenges were identified, including: small, non-random, convenience samples; reliance on descriptive and bivariate analyses; and a dearth of longitudinal research. Robust evidence regarding causal relationships between predictor variables and carer outcomes is lacking. Findings suggest the need for knowledge regarding: family caregiving for patients with non-malignant terminal conditions; whether needs and outcomes differ between family caregivers at the end of life and comparison groups; and caregiver outcomes in bereavement. Clear definitions of ‘family caregiving’, ‘end of life’, and ‘needs’ are required as well as greater application and testing of theoretical and conceptual explanations.

Keywords

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

Introduction

Family caregivers represent the backbone of health and social care delivery in countries throughout the world, including Western or developed countries. For instance, in Canada, it is estimated that family caregivers provide 80–90% of all care provided to individuals in home settings;¹ in Australia, the unpaid workforce of family caregivers has been estimated at about five times the equivalent of the full-time paid

care provider workforce² and would cost about \$30.5 billion if substituted with formal, paid care.³ An estimated 500,000 people provide care at the end of life in the UK,⁴ and the overall number of caregivers with heavy caring commitments is over one million, a figure similar to the number of those employed by the National Health Service.⁵ While many family caregivers wish to provide care, they often face considerable burden and distress^{6–10} and are expected to take on

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increasing amounts of the complex care that were once provided by nurses in the home;^{9,11} this is compounded by a dearth of health services available to some caregivers.¹² Owing to the importance of family caregivers in supporting ill and dying persons, considerable attention has been paid to the topic in gerontological, nursing, and health services research, and family caregiving is identified as a top international research priority in palliative and end of life care.¹³ Academic interest is paralleled at political and policy levels as government agencies seek to understand family caregiving in order to promote and support it, in the belief that it will reduce costs.

The majority of the academic focus in the caregiving literature is on care for frail elderly seniors and those with chronic conditions. There is less research that focuses on care for individuals in an identifiable terminal stage of illness; the ‘fuzziness’ of palliative and end of life terminology is an acknowledged challenge in this regard. The need for a review of the most recent research in family caregiving at end of life (i.e., the last 10 years) is especially important as the context of home-based palliative care has been changing over the last decade.¹⁴ There has been increasing emphasis on home death in many Western countries, along with increasing proportions of clients with non-malignant disease requiring palliative care services and often increasing demands on family caregivers. For instance, the UK’s End of Life Care Strategy¹⁵ emphasizes patient choice for place of care and death: for a majority of patients this will be home.

Quantitative approaches to the study of family caregiving at end of life contribute to our ability to generalize research findings, given that such studies tend to draw upon large, representative samples. Quantitative studies examine association, causality, and the influence of multiple variables on specified outcomes. Given the different purposes and paradigms underlying qualitative research (e.g., rich and nuanced understanding, development of theoretical explanations), that body of literature will be reviewed in a separate publication.¹⁶

The purpose of this comprehensive review is to synthesize recent quantitative research on home-based family caregiving for those with terminal conditions (including, but not restricted to cancer). Most of the last year of life is spent at home¹⁵ and this is where the majority of patients wish to be cared for and to die.¹⁷ By specifically targeting this body of research, we aim to identify distinguishing features of home-based family caregiving at end of life and provide a summary of context-specific information to plan future interventions and inform policy development. As such, this review should be distinguished from reviews that include facility settings (including in-patient hospice), studies of family members who

are not identified as caregivers, or studies where death of the care recipient is not an expected outcome. While some useful insights can be gleaned from such research, this review will provide more specific information of direct relevance to home-based family caregiving at end of life. We also aim to identify gaps in existing knowledge where additional research, as well as methodological and conceptual refinement, is warranted.

Methods

We conducted a comprehensive review of empirical research on family caregiving for individuals with terminal conditions, published between January 1998 and August 2008. This 10-year period was used in order to assess the most recent contributions to this field of research, though we acknowledge the significant contributions to knowledge made by reviews prior to 1998, including, for instance, a review by Kristjanson and Ashcroft.¹⁸

Inclusion and exclusion criteria

A systematic approach was employed, applying several inclusion and exclusion criteria.

- (1) Included studies were required to use samples of family caregivers (and in particular, to indicate this in their sample criteria or recruitment description, which was reviewed by two researchers for this purpose). Thus, articles focusing only on ‘family members’ with no indication of caregiving were excluded. For the purposes of this review, we relied on authors’ use of the term ‘family caregiver’ for inclusion. Further, both co-resident and non co-resident family caregiving studies were included.
- (2) Included articles were required to address a palliative, terminal, or otherwise ‘advanced’ or ‘end-stage’ phase of care (identified by two researchers, based on recruitment details). For dementia, patients were to be specified as late stage or Mini-Mental State Examination¹⁹ score = 0; for heart failure, New York Heart Association Class III or IV. If the study did not specify the stage of disease or did not provide information that would enable us to identify it as addressing a palliative phase of care, the article was excluded.
- (3) Research focusing on family care for dying individuals in facility settings was excluded (i.e., the majority of patients were institutionalized for the duration of the study, in inpatient hospices, hospitals or nursing homes). We included articles that could be characterized as focused primarily on

home-based caring (two researchers independently coded for setting, relying on sampling and recruitment information as well as an overview of the findings). Several studies recruited from both inpatient and outpatient settings, but did not describe how many caregivers were recruited from each, nor did they differentiate clearly in their findings between the two settings.^{20–27} However, these papers were included as their findings showed clear relevance to home-based settings of care. Lastly, some papers^{28–30} did not specify the setting in which caregiving occurred, but based on an assessment of the relevance of their findings to home care, they were included in the review.

- (4) Because we were also interested in issues of bereavement among family caregivers who had provided care at the end of life, we included literature with bereaved samples. However, information provided within retrieved articles was frequently insufficient to determine whether caregivers had provided support during a defined palliative or end of life stage. For the purposes of this review, unless the article clearly indicated that caregiving had occurred in situations involving expected death or a defined palliative or terminal phase, it was excluded. Two researchers coded this information, relying first on study abstracts, then on the recruitment and methods sections of the full papers, where more details were necessary.
- (5) Only quantitative research and mixed method research with quantitative findings were included. Two researchers coded this information, relying on study abstracts and the findings from full papers, where necessary.

Further exclusions entailed: non-empirical and non-peer reviewed research; policy documents; dissertations; presentation abstracts; paediatric palliative care; and studies that focused on family caregivers' proxy accounts of patient care (including caregiver-patient comparisons, e.g., of patient pain ratings), except where findings were directly relevant to family caregiving outcomes.

Articles focusing solely on measurement development and validation (seven potential were identified) were also excluded from this review, although one³¹ that contained information of direct relevance to understanding family caregiving was included.

Articles were restricted to those written in English. Exclusions were not made on the basis of assessments of the rigor, validity, and reliability of studies and their findings, as would be typical in a systematic review. Indeed, most research on caregiving at the end of life is difficult to grade using traditional levels of evidence for systematic reviews.³²

Searches

Searches were performed in August 2008 using the following databases: Pubmed; AARP Ageline; Web of Science; Science Direct (Elsevier); Health Sciences SAGE fulltext; Medline (OVID, 1996–present); Cinahl; Healthsource (nursing/academic); Caresearch; Academic Search Premier; Anthropology Plus; Anthrosource; Social Sciences Index; Sociology SAGE fulltext edition; Sociological Abstracts; Geobase; PSYCinfo; Psychology SAGE fulltext edition; PSYArticles; Cochrane Database of Systematic Reviews/Cochrane Central Register of Controlled Trials; Health Technology Assessment Database; and the Database of Abstracts of Reviews of Effects. Some of the databases searched would not permit highly complex searches, in which event searches were split into smaller component parts and repeated.

Because our primary interest was in articles that address both family caregiving and palliative/end of life, our first search utilized terms referencing 'family caregiving' (e.g., 'informal carer', 'family AND carer') as well as at least one of a variety of palliative terms (e.g., 'terminal', 'palliative', 'end of life', 'dying', 'hospice'). Given the difficulty in identifying family caregiving at end of life for non-malignant diseases, a supplemental search was performed using the family caregiving terms and selected non-malignant disease terms: dementia, cognitive disorders, Alzheimer's Disease, organ/system failure, heart failure/heart disease, COPD [chronic obstructive pulmonary disease], pulmonary disease, lung disease, respiratory tract disease, Parkinson's disease, HIV/AIDS, neurodegenerative, and amyotrophic lateral sclerosis. Another supplemental search was performed to ensure the inclusion of studies addressing bereavement and grief among family caregivers who had provided care during a palliative phase of care. This search included the family caregiving terms and 'bereavement' or 'grief'. We further supplemented these database searches with a search of our own existing personal bibliographic databases, as well as a Google Scholar search. A manual search for additional articles identified in the reference lists of included articles was also performed.

Review strategy

The review proceeded in two stages, with the inclusion/exclusion criteria applied at both stages.

Phase 1. First, abstracts were imported and organized using bibliographic management software and examined to determine inclusion on the basis of the two core criteria: family caregiving and end of life. If there was no information provided to confirm these

criteria, the article was excluded. If these criteria were confirmed but the abstract indicated that the article came under any of the other above-mentioned exclusion criteria, it was removed.

Phase 2. If abstracts were not rejected during Phase I, full articles in the included list were retrieved and reviewed in-depth to make final inclusion/exclusion decisions using all of criteria outlined above. Then, articles that remained after this screening were reviewed in order to systematically code the following data: sample size; methods of data collection and analysis; caregiver definition; patient population; and country of origin. In addition, we extracted information regarding: the study's research focus; sample and recruitment; definition of family caregiver; caregiver status (bereaved or current); methods of data collection; methods of analysis; key findings related to family caregiving (commonly, this entailed the associations identified as statistically significant, as well as core descriptive findings); and theoretical or conceptual frameworks. Lastly, the key findings for the total number of articles were synthesized into this review, by grouping and coding them thematically, with a focus on providing an overview of the primary types of findings (i.e., the most commonly reported substantive topics addressed).

Results

Methodological overview

In total, we identified 123 articles reporting quantitative findings, including 17 mixed methods studies. Table 1 summarizes methodological characteristics of the reviewed articles.

A surprisingly large number of studies (82; 67%) did not define 'caregiver' or only minimally defined the term (e.g., 'unpaid family or friend caregiver'). Care itself was rarely defined, although, for instance, Bernard and Guarnaccia³³ and Walsh et al.³⁴ specifically mention both emotional and practical/caretaking support. Twenty-five articles (20%) define a caregiver as the person most or primarily involved in the patient's care, or providing the most or the majority of care, help, or assistance. In seven studies (6%), the person 'most responsible' or 'assuming the main responsibility' (e.g., Cameron et al.,³⁵ McLaughlin et al.,³⁶ Scott³⁷) is mentioned. The remaining nine studies (7%) used various other definitions. A few studies also used a minimum task or time commitment in their definitions: for instance, Chan and Chang³⁸⁻⁴⁰ specify at least weekly caregiving responsibility for more than 2 months; Ladner and Cuellar⁴¹ and Loke et al.,⁴² at least 8 hours a day; Payne et al.,⁴³ more than 20 hours per

week; and Cameron et al.,⁴⁴ help with at least two caregiving tasks. Caregiver samples were identified through a variety of means: by caregivers themselves, patients, or formal service providers; from patient charts or death certificates; or by the researchers using explicit criteria. In addition, samples for the most part were non-random, convenience samples of volunteers, commonly recruited from the patient lists of formal service providers.

The majority of studies ($n = 72$; 58%) focus on caregiving for cancer populations, although this may be a methodological artefact (i.e., an identifiable terminal phase of illness is more common for patient populations with cancer diagnoses). The actual number of cancer-focused articles may be even higher, as an additional 16 articles (13%) do not specify the patient population but recruited caregivers from those receiving hospice services.

Sixty-eight (55%) of the articles were based on findings from samples of 'current caregivers' (i.e., actively providing care at the time of participation in the study, as opposed to bereaved participants: Table 1); 67 (54%) of studies had sample sizes of under 100 (Table 1). Specifically, 10 studies (8%) had sample size totals of less than 25; 28 (23%) had 25-49; 29 (24%) had 50-99; 29 (24%) had 100-199; 16 (13%) had 200-499; and 11 (9%) had over 500 respondents. Sample size may have influenced the statistical methods that researchers could employ. Twenty-two studies (18%) employed only descriptive or univariate statistical analyses and for only 46 (37%) studies could the level of statistical analysis be described as multivariate (Table 1). The most common form of data collection was a self-administered or mailed questionnaire, used by 55 (45%: Table 1). The geographic location of study samples is also outlined in Table 1. In addition, (information not included in the table), 39 studies (32%) were identified as including multiple time points of data collection. Of these, 15 studies included two time points; nine studies included three time points; eight included four time points; and seven studies included five or more points of data collection. The length of time between data collection points varied widely between studies and within studies between different time points. For instance, some studies changed the timing of data collection when the patient's functional status declined or described collecting data when a predetermined time had elapsed since the patient's death.

Conceptual overview

The three most commonly cited theoretical frameworks were psychological and focused on caregiver coping: (i) Pearlin's Stress Process Model,^{45,46} (ii) Lazarus and Folkman's stress and coping framework,^{47,48} and

Table 1. Descriptive summary of quantitative studies (n = 123)^a

Characteristic	n (%)	References
Definition of caregiver		
Undefined or minimal definition	82 (67%)	7,20,21,24,27–29,31,43,52–61,64,66,67,68,71,72,74–78,79,83–91,94,95,96,98,99,101,106,107,109,112,113,115–126,128,129,131,132,133,135,136,149–160
The person most or primarily involved in patient care	25 (20%)	22,23,25,26,30,33,44,65,69,70,73,92,100,102–105,108,127,130,137,161–164
The person ‘most responsible’	7 (6%)	35,37,42,93,97,111,114
Other definitions (various)	9 (7%)	34,38–41,62,110,165,166
Total	123 (100%)	
Patient conditions		
Cancer	72 (58%)	7,22,23,25,26,30,31,33–35,38–40,42–44,52–56,59–62,70–73,75–78,83,87,88,90,91,94,96–98,102,103,105–107,109,111,116,118,120,121,124–127,129,130,133,137,149,150,152,153,155,156,159–161,163,164
Dementia	2 (2%)	114,151
HIV/AIDS	2 (2%)	21,165
Organ/system failure	4 (3%)	20,37,67,100
Neurodegenerative	3 (2%)	66,89,157
Multiple patient populations	21 (17%)	24,27,41,64,68,69,74,86,95,104,110,112,113,115,122,123,131,132,139,158,162
Not specified, service recipients ^b	16 (13%)	28,29,57,58,79,84,85,99,101,108,119,128,132,135,136,166
Not specified	3 (2%)	65,92,93
Total	123	
Caregiver status		
Bereaved	32 (26%)	20,21,27,33,64,67,68,78,86,87,88,93,95,104,108,109,110,112,113,114,115,116,117,118,126,129,131,133,136,157,160,163
Current	68 (55%)	7,24,26,28,31,34,35,37–44,52–54,56–62,66,69–77,89–92,94,96–101,103,105–107,119–122,124,127,130,137,149–152,154,156,158,159,162,164
Both/transition over time	21 (17%)	22,23,25,29,30,56,65,79,83–85,102,111,123,125,128,132,153,155,161,165
Other sample used	2 (2%)	135,166
Total	123 (100%)	
Sample size		
Less than 25	10 (8%)	37,42,54,71,97,101,113,156,157,159
25–49	28 (23%)	7,35,38–41,43,44,53,57,59,61,77,84,85,88,91,94,109,119,121,122,124,125,130,149,153,158
50–99	29 (24%)	24,29,31,56,58,62,64,67,69,70,72,74,76,83,98,100,103,104–106,114,115,127,129,151,152,155,162,164
100–199	29 (24%)	20,21,23,24,26,28,30,52,55,60,68,75,86,87,96,107,108,111,112,115,118,123,128,131,133,151,161,165,166
200–499	16 (13%)	22,27,33,34,66,73,89,90,102,117,120,126,132,135,137,163
500+	11 (9%)	65,78,79,92,93,95,99,110,116,154,160
Total	123	
Highest level of analysis		
Univariate	22 (18%)	19,41,42,53,54,68–70,87,88,115,100,122,123,125,128,150,156,158,159,163,164
Bivariate and group comparison	53 (43%)	7,21,22,28,29,31,33–36,38–40,43,44,52,56,59,65–67,72,74,77,78,84,85,87,90,91,98,103–106,108,109,113–115,117,118,121,122,128,131,133,135,151,156,159,164–166
Multivariate	46 (37%)	23–27,30,37,55,57,58,60–62,64,68,73,75,76,79,83,86,92–97,99,100,102,107,110,111,112,119,120,125,127,132,136,137,150,152,154,160,161
Other	2 (2%)	31,153
Total	123 (100%)	

(continued)

Table 1. Continued

Characteristic	n (%)	References
Data collection		
Survey (unspecified)	6 (5%)	44,96,102,111,118,136
In person interviews	58 (47%)	7,20,22–26,28–30,33,35,37,41–43,52,53,55,57,61,62,64,65,69,71,73,74,78,84,88,90,92,94,97,101,103,104,110,113,114,119,124,127,128,130,137,149,150,154–157,159–162,164,165
Telephone interviews	19 (15%)	20,26,35,53,60,68,86,87,93,95,103,106,109,112,117,122,132,150,159
Self-administered or	55 (45%)	7,21,24,28,29,31,34,38–40,43,52,54–56,58,59,64,66,67,70–72,75–77,79,83,85,89,91,98–100,105,107,108,115,120,121,123,125,126,129–131,133,151–153,155,157,158,160,163
Other or not described	13 (11%)	54,60,93,95,107,108,116,121,135,136,153,164,166
Total	151 ^c	
Country		
USA	55 (45%)	22–30,33,37,41,53,54,57–60,65,74,75,79,84,87,88,90–93,95,98–100,102,103,106,109,113,114,120,121,128,130,131,135,137,149,150,154,156,158,159,161,164,165
Canada	14 (11%)	21,35,44,68,73,85,86,97,105,107,112,117,132,153
UK	19 (15%)	20,34,43,67,78,94,101,104,115,117,119,122–124,126,133,136,157,166
Australia	12 (10%)	7,52,55,56,61,66,69,71,89,110,111,127
Europe	15 (12%)	31,62,64,70,72,76,77,83,96,108,125,152,155,160,163
Asia	6 (5%)	38–40,42,129,151
Africa, Middle East	2 (2%)	118,162
Total	123 (100%)	

^aInformation not included in the table: 39 studies included multiple time points of data collection.

^bThese are most likely to be cancer as they were recruited clients from hospice or palliative care services; however, the author(s) did not specify.

^cCell totals for method of data collection do not total to 123, as articles were assigned more than one code, for instance, if both in-person and telephone interviews were used.

(iii) the Transactional Model of Stress and Coping.^{49–51} These models were explicitly discussed and applied (sometimes in modified form) to explain outcomes among family caregivers at end of life by Burns et al.,⁵² Cameron et al.,³⁵ Carter,^{53,54} Chan and Chang,³⁸ Haley et al.,²⁴ Hudson et al.,^{55,56} Meyers and Gray,⁵⁷ Mickley et al.,⁵⁸ and Redinbaugh et al.⁵⁹ Such models focus on identifying background characteristics, primary and secondary caregiving stressors, subjective appraisals, and mediators that are important for caregiving coping outcomes. Less common but also used was Nijboer's Family Caregiver Model (adapted and/or applied by Given et al.,⁶⁰ Cameron et al.,⁴⁴ Sharpe et al.,⁶¹ and Mystakidou et al.⁶²). This model examines how patient and family caregiver characteristics as well as patient symptoms influence caregiver outcomes. Additional models varied depending on the particular focus of studies; examples are provided in Table 2.

The majority (93; 76%) of articles did not clearly explicitly articulate a theoretical or conceptual framework that guided their studies, hindering efforts at classification. Some remained descriptive without testing explanatory models, beyond suggested hypotheses.

Others included independent variables in a statistical model without theoretical rationale (e.g., selecting those with demonstrated empirical links in other existing research).

Family caregiver outcomes such as physical and mental health (including depression), burden and rewards, quality of life, and bereavement adjustment are commonly the topic of interest. Predictive models most often included: caregiver characteristics; demographic characteristics of patients; disease-related characteristics and symptoms; coping resources such as self-efficacy and coherence; subjective appraisals and caregiving assessments; and to a lesser extent, features of the caregiving experience (e.g., workload, setting). Implicitly, many studies employ at least some of the concepts and theories expressed in the psychological models identified above.

The focus for analysis is overwhelmingly the individual, and to a lesser extent, the caregiver–patient dyad; in far fewer studies, researchers considered broader or more contextual features of caregiving, including: variables representing relationships between care recipients and caregivers; available informal and formal supports; or organizational or institutional features of care.

Table 2. Overview of selected conceptual and theoretical frameworks

Framework	References
Pearlin's Stress Process Model ^{45,46}	24,35,38,52–59
Lazarus and Folkman's stress and coping framework ^{47,48}	
Transactional Model of Stress and Coping ^{49–51}	
Nijboer's Family Caregiver Model ¹⁶⁷	44,60–62
Wright et al.'s Illness Belief Model ¹⁶⁸	105
Devins' Illness Intrusiveness Model ¹⁶⁹	44
Bowlby's Attachment Theory ^{170,171}	107
Bandura's Self-Efficacy Theory ¹⁷²	106
Relief Model of Bereavement; Complicated Grief Model ¹⁷³	102
Hogan's Model of Bereavement ¹⁷⁴	159
Health Related Quality of Life Model ¹⁷⁵	37
Smith's Model of caregiving effectiveness ¹⁷⁶	
Porter's Discrepancy Theory ¹⁷⁷	127
Roy Adaptation Model ¹⁷⁸	113
Hospice Experience Model of Care ^{179,180}	79,99

Few studies include variables reflecting broader organizational, cultural, economic, or political contexts, although some do so indirectly by comparing different groups.

Alongside a focus on psychology, coping, and well-being, a substantial portion of research could be characterized as rooted within a health services research paradigm. While not a theoretical framework per se (e.g., for explaining relationships among concepts), such research tends to be oriented to the goal of informing policy and changing practice, for instance by identifying formal service needs in particular populations, and evaluating the outcomes of programmes, services, and interventions.⁶³

Synthesis of quantitative findings

In this section, we synthesize the findings reported in the quantitative literature in family caregiving at end of life. The key findings of each study were identified from the abstract and supplemented based on a review of the full article. Then, categories were derived by grouping and coding these key findings thematically.

Needs assessments and impacts of family caregiving at end of life. Family caregivers provide extensive help to dying individuals (e.g., Visser et al.,⁶⁴ Wolff et al.⁶⁵) in a number of areas, including, for example: domestic chores;²⁰ household tasks and instrumental activities of daily living;^{7,66,67} personal care and activities of daily living;^{20,67–69} and medications and symptom management.^{7,67} The majority of studies identify caregiver support needs. Some use self-report scales that directly measure various support needs (e.g., Osse et al.⁷⁰) or

more particular needs (e.g., Kristjanson et al.⁷¹ measured needs for night respite). Most often, however, need is inferred from (and conceptually equated with) various subjective and objective indicators of caregiving difficulty, burden, depression, mental and physical ill-health, and, to a lesser extent, barriers to service access, dissatisfaction with formal services, and a lack of informal support. In other words, authors often purport to assess and examine caregiver needs, yet operationalize the concept by relying on these other indicators. Further, not all studies clearly differentiate between patients' needs and family caregivers' needs, describing them as if they were similar. Lastly, the ways in which needs are described in such studies tends to imply that there are common needs for all caregivers, whereas Osse et al.⁷⁰ for example, note that despite some commonalities, there was considerable diversity in caregivers' individual needs.

Many of the data used to draw conclusions about caregiver needs focus on the extensively documented challenges, burdens, and negative outcomes that can be associated with caring for a dying family member. As a general overview, research we reviewed identified moderate to high levels of emotional and psychological difficulties, financial strain, occupational disruption, activity restrictions, social dysfunction and relationship challenges, challenges with patient care and household tasks, communication with health care providers, and negative physical health impacts (see Table 3 for an overview of findings, with references).

Few studies make explicit comparisons between the needs of family caregivers to those at end of life and either caregivers to the chronically ill (e.g., not a palliative phase of care) or non-caregiving family members

Table 3. Overview of needs and/or impacts

Needs and/or impact	References
Psychological difficulties	
Depression and anxiety	7,24,41–43,60,66,77,84,97,121,122,137,150
Feelings of powerlessness and helplessness	163
Low caregiver esteem	91
Physical and emotional stress	38,101,122
Psychosocial difficulties	671,79,166
Financial and occupational difficulties	
Occupational disruption	67,97,103,160
Financial strain; need for financial support/advice	69,87,95,103,153,157,160,162,166
Activity restrictions	7,42,68,78,98
Social dysfunction and relationship challenges	28,42,66
Patient care difficulties	
Need for direct help or guidance regarding practical aspects of care	92,132,155
Being able to leave patient unattended	77
Dealing with physical demands of providing care	42
Needs for respite	69,71,132,158,166
Needs for help with household tasks	69,92,132
Needs for communication and information	69,70,155
Physical health impacts and challenges	7,28,68,104
Sleep disturbances and insomnia	53,54,66,84,121,150
Fatigue	124
Negative impacts on quality of life, life satisfaction, and high burden/strain	24,43,57,77,91,95,108
Rewarding and/or meaningful outcomes	7,19,64,66,76–78

(or indeed, to population norms for certain indicators). Grov et al.⁷² reported that while physical quality of life was better than the norm, anxiety was significantly higher. Others who made comparisons to the general population and/or non-caregiving control samples also identify worse mental health outcomes^{28,69,73,74} and in some cases worse physical health^{28,74} among caregivers. In two studies comparing family caregivers providing care for those with terminal conditions with those providing care for those with non-terminal conditions, the former had worse quality of life;⁷⁵ Weitzner et al.⁷⁵ also noted worse physical, but not mental, health in the palliative care group. As an exception, in two studies by Grov and colleagues,^{72,76} neither overall quality of life nor depression differed significantly between caregivers and the population norm.

In addition to the challenges and burden of providing care to a loved one at the end of life, several researchers have noted that some caregivers appraise the experience as rewarding and/or meaningful,^{7,20,65,66,77,78} often simultaneously with challenges and burden. Salmon and colleagues⁷⁹ focus on such ‘transformative aspects of caregiving’ as self-acceptance, meaning and closure; which were associated

among bereaved caregivers with reduced burden and an enhanced sense of gain. These kinds of reported benefits may represent the outcomes of caregivers’ active attempts to cope with their role.^{80–82}

Bereavement: the impact of grief and role loss. We know little about how providing care during a terminal phase of illness affects bereavement outcomes differently than providing care for those with unexpected or sudden deaths (i.e., that may have been preceded by chronic illness, disability, or frailty). The few studies we did identify as addressing bereavement after a period of palliative care (i.e., a terminal phase) are summarized here and serve to inform other research that identifies needs for bereavement support, at least among some caregivers.

Overall, this research reports mixed outcomes in bereavement. Rossi Ferrario and colleagues⁸³ identify an increase in perceived problems 1 year after death. In one study on bereavement,⁸⁴ family members providing care to those at end of life had some diminishment of distress and anxiety, but increases in loneliness and sadness and continued sleep disturbances after the death. Further, Mackenzie et al.⁸⁵ found a mixed pattern of

improvement and worsening of cognitive functioning in bereaved caregivers.

Other research highlights positive outcomes that can occur in bereavement. For instance, Cadell²¹ while noting that 86% of the bereaved caregiver sample experienced post-traumatic stress symptoms, 82% also reported scores indicative of simultaneous post-traumatic growth. Salmon et al.⁷⁹ noted that current caregivers reported a greater sense of existential meaning within their role, but bereaved caregivers reported higher self-acceptance, closure and gain, as well as better health and lower burden. In other studies, bereaved caregivers, while struggling with sleeplessness, depression, loss of appetite, and low mental health^{68,86,87} also commonly reported they were coping well,^{68,88} can identify positive outcomes,⁸⁸ tend to have moderately positive outlooks and low negative reactions to caring,⁸⁷ and high physical health.⁸⁶ Lastly, Chentsova Dutton et al.,²⁹ who examined bereavement adjustment over time with a comparison involving non-caregiving controls, concluded that, overall, depression and psychological distress are worse for bereaved caregivers during the caregiving period and the first few months in bereavement, but then improve.

Moving towards explanations: identifying predictors. The above studies provide descriptive information and assist in the identification of formal support needs. As outcomes vary considerably between individuals, however, many researchers seek to identify predictors of caregiver outcomes. The underlying aim may be the identification of particular caregivers that have higher needs for formal service intervention. In this section, we identify the general groupings of factors reported as correlated with a wide range of negative family caregiver outcomes (e.g., burden, quality of life, and depression). Unless otherwise indicated, the studies reported in this section use cross-sectional designs; assumptions regarding causal directions must be made with caution.

Patient socio-demographic and clinical characteristics are factors associated with caregiver outcomes. For example, caregivers of younger patients have been identified as reporting more psychological distress in one longitudinal study⁷³ and task difficulty⁴⁰ in a cross-sectional study. For example, caregiver stressors may differ depending on the nature of the illness. Kristjanson et al.^{66,89} compared differing groups of caregivers for those with selected neurodegenerative conditions (motor neuron disease, multiple sclerosis, Huntington's disease, and Parkinson's disease). Caregivers for individuals with motor neurone disease reported the lowest quality of life and, together with caregivers for individuals with Huntington's, had high levels of health problems compared to other groups.

Meyers and Gray⁵⁷ reported better quality of life among caregivers of patient conditions other than neurological disease, as well as lower burden among caregivers of patients with renal disease. In another study, Haley et al.⁷⁴ compared caregiving for patients with dementia versus cancer at the end of life. Despite differing stressors, there was little difference between the groups in psychological distress and physical health. More generally, as the patient's health and function deteriorates and care needs, symptoms (including pain, delirium), and distress increase and worsen in severity, caregiver quality of life is found to worsen,^{66,75} and strain, psychological distress, depression, anxiety, and burden increase, as identified in several cross-sectional^{59,79,90-95} and two longitudinal^{60,73} studies. Further, one cross-sectional study⁹² and one longitudinal study⁶⁰ documented lifestyle interference; a longitudinal study by Gridelli et al.⁹⁶ indicated increased costs (in terms of hours of care) with increasing patient symptom severity.

Such findings are supported by other research that has identified a worsening of caregiver outcomes such as depression/anxiety, quality of life, and burden as diseases progress towards the terminal stage and death^{31,57}; this is confirmed in two longitudinal studies.^{77,97} However, there are exceptions: in two separate longitudinal studies, Aranda and Hayman-White⁷ found no change over time in depression/anxiety and Clark et al.⁹⁸ reported no change in caregiver quality of life and burden. Increasing care burdens associated with the approaching death of the care recipient over time may also be buffered in part by increasing levels of caregiver exposure to the role and experience with task performance: for example, Chan and Chang³⁸ noted more negative responses to stress among caregivers that had a shorter time frame of experience providing care.

A number of caregiver socio-demographic characteristics have also been the focus of research and are identified as important (perhaps the most important) for caregiver outcomes, although findings are often mixed or lack sufficient attention to explanations underlying observed associations, as well as to interaction and mediation effects.

Whilst Kwak and colleagues,⁹⁹ in longitudinal research, found that younger caregivers reported more comfort, closure, and satisfaction from caring, this is something of an exception within the literature reviewed. Instead we are led more to the conclusion that younger caregivers experience more emotional strain and psychological distress (Dracup et al.,¹⁰⁰ Payne et al.,⁴³ and one longitudinal study by Dumont et al.⁷³), more reported task difficulty,⁴³ greater impact of stressors,¹⁰¹ and greater caregiving burden and strain more generally.⁹⁵ However, a longitudinal examination by Given et al.⁶⁰ indicated higher depression and sense

of abandonment among middle-aged caregivers in comparison to both younger and older age groups. Findings regarding age are often complicated by the fact that older caregivers are more likely to be caring for spouses and younger caregivers to be caring for parents. Caregiving daughters were in one study identified as having lower burden⁵⁷ than sons, husbands or wives, but in one longitudinal study¹⁰² as having greater role strain than husbands. Adult child caregivers may have generally higher depression, sense of abandonment, and disrupted schedules (a longitudinal study by Given et al.⁶⁰). In another longitudinal study,²⁰ spousal caregivers were less likely to find caring rewarding.

Regarding caregiver gender, Scott et al.¹⁰¹ noted that men were more adversely affected by material and social consequences of caring and Grov et al.⁷² reported poorer mental quality of life in male caregivers. In contrast, and reflecting more general population findings, women providing palliative care to family members have been identified as experiencing greater depression^{24,28,74} as well as higher caregiver strain and psychological morbidity,^{24,43,93} burden,⁷⁹ psychological distress (a longitudinal study by Dumont et al.⁷³), sense of abandonment (a component of burden identified by Given et al.⁶⁰ in a longitudinal study), and lower life satisfaction.²⁴

Caregiver ethnicity and socio-economic status may also play a role: Phipps et al.¹⁰³ in a longitudinal examination, noted that initial adjustment to caregiving was more difficult for Caucasian compared to African American caregivers, although the latter reported worse health. In another study, Caucasian caregivers reported greater strain in comparison to Asians.⁹⁵ However, Koffman and Higginson¹⁰⁴ reported that Afro-Caribbean caregivers in the UK, compared to Caucasians, had greater perceived daily life restrictions and reported greater needs for financial assistance (the two groups were similar in terms of reported stress). Caregivers with lower education have been identified as experiencing greater stress,³⁸ distress,⁴⁴ and poorer physical health,⁷⁵ but in another study lower education is associated with lower burden.⁷⁹ Other research suggests that retired caregivers may have better quality of life and lower burden,⁵⁷ whereas the employed may have higher depression (Given et al.,⁶⁰ a longitudinal study). However, Grov et al.⁷⁶ reported that employment was associated with higher quality of life. Lastly, when caregivers are in better physical health, they may have better outcomes in terms of lower depression and higher life satisfaction²⁴ and lower burden.⁷⁹

There has been a particular focus on associations and potential causal links between caregiver appraisals and coping strategies and caregiver outcomes. In fact, Aranda and Hayman White,⁷ drawing on longitudinal findings, argue that personal reactions are more

important than patient characteristics (level of dependence, symptoms) for caregiver outcomes such as depression and anxiety. Features of appraisal and coping that have been associated with positive caregiver outcomes (e.g., life satisfaction, reduced depression, caregiver burden and strain, and health-related quality of life) based on cross-sectional research include: appraisals of the benefits of caregiving;²⁴ sufficient preparation;³⁷ fewer self-care problems;²⁴ lower reported task difficulty;³⁸ and pain controllability;¹⁰⁵ reported greater comfort with tasks and meaning in caregiving;⁷⁹ caregiving role esteem³⁷ and self efficacy or confidence;¹⁰⁶ 'reframing coping' strategies such as acceptance and redefinition;⁵⁹ positive religious appraisals;⁵⁸ and the caregiver's own subjective appraisals of burden.¹⁰⁷

Characteristics of the caregiving context at end of life (i.e., particular locations, arrangements, and levels and types of care) may also have an impact on caregiver outcomes, although it is generally accepted that the objective features are less important than their subjective appraisals. As well as the particular caregiving stressors associated with the patient disease type and trajectory noted above, Dracup et al.¹⁰⁰ reports that the level of control of spousal caregivers is associated with higher emotional wellbeing. We can also consider the setting of and nature or intensity of care, including whether care is co-resident or not, and whether there is a home death. Within the literature we reviewed it is uncertain whether and how co-residence with the care recipient relates to caregiver outcomes: Fromme et al.⁹³ note that co-resident caregivers reported less strain. However, Carlsson and Rollison¹⁰⁸ report higher burden with home deaths as opposed to hospice deaths and greater financial strain has been associated both with co-residence in one longitudinal study⁹⁶ and home death¹⁰⁹ in a cross-sectional study. Associations in this regard are difficult to interpret, given selection effects: for instance, Visser et al.⁶⁴ report that care recipient home death (as an outcome) was associated with having a primary caregiver who felt less burdened and suggest more burdened caregivers may be more likely to institutionalize care recipients.

Some research has also suggested that where caregiving at the end of life involves more disruptions and restrictions to daily activities there may be greater burden⁶⁸ and emotional distress.⁴⁵ Further, Abernethy et al.¹¹⁰ reported that the level of care provided was correlated with unmet needs during caregiving and Brazil et al.⁶⁸ found an association between level of assistance with activities of daily living and burden outcomes.

Overall, research on home-based family caregiving at end of life has considered patient characteristics, including disease type and trajectory, caregiver characteristics, caregiver appraisals and coping strategies, and

the setting and/or intensity of care as potential factors explaining variance in caregiver outcomes. Far less often, studies include other independent variables in their models, although findings from such studies suggest the potential for broader influences on caregiving outcomes, ranging from relational influences such as marital satisfaction (e.g., Braun et al.¹⁰⁷), to available support (e.g., Salmon et al.⁷⁹ and a longitudinal study by Sharpe et al.⁶¹), organizational features of health care institutions (e.g., Meyers and Gray⁵⁷), and features of interaction with the health care system and providers (e.g., Emmanuel et al.⁹²).

Predictors of bereavement outcomes. Several studies associated higher pre-loss emotional distress, burden, the intensity of the level of care, and caregiving problems with bereavement maladjustment and psychological wellbeing in bereavement, including several longitudinal or population-based studies.^{25,83,110,111} Other correlates of negative or risk outcomes in bereavement include: being a spouse,¹¹² confirmed in longitudinal research by Rossi Ferrario et al.,⁸³ and being female, in a longitudinal study,¹¹¹ low social support,⁸⁶ and co-residence, for daughters.³³ Being an older caregiver was significantly linked with negative outcomes in two cross-sectional studies^{86,113} and one longitudinal study,⁸³ however, longitudinal work by Bernard and Guarnaccia¹⁰² and cross-sectional research by Brazil et al.¹¹² challenges this association. Owen et al.¹¹⁴ found that African American caregivers, as opposed to Whites, reported less acceptance and greater perceived loss. In addition, in longitudinal research studies, negative bereavement outcomes were associated with coping both by accepting responsibility or by avoidance,¹¹¹ negative relationship quality,¹¹¹ low religiousness,³⁰ past bereavement experience,¹¹¹ childhood separation from parental figures,¹¹¹ and perceptions of inadequate end of life support and high patient symptom severity/suffering.¹¹⁵

Addington-Hall and Karlson¹¹⁶ found that when patients died at home, bereaved caregivers had higher psychological distress and related outcomes. Yet, others have associated increased bereavement grief with hospital death³³ and home deaths with better mental and physical health in bereavement.^{86,115} Work by Bernard and Guarnaccia,³³ including one longitudinal study,¹⁰² also suggests the importance of gender and/or relationship interaction effects and differences in bereavement patterns and outcomes.

In bereavement, there may be greater tendency to report satisfaction with the place of death even if it was not the original preference.¹¹⁷ However, Carlsson and Rollison¹⁰⁸ indicated that caregivers of those who died at home appeared more satisfied with their achievement and Hunt Raleigh et al.¹¹³ noted that all

were satisfied with the decision to provide care at home; further, Singer et al.¹¹⁸ found that, despite reported challenges, over 90% of bereaved caregivers reported satisfaction with the caring experience when death occurred at home with the assistance of a homecare programme, compared to 61% when the care recipient died in hospital.

Service evaluations and interventions. Several studies, most often embedded in a health services research paradigm, assessed or evaluated particular programmes, services and interventions designed to enhance outcomes for family caregivers providing palliative care. These are reviewed in Table 4. The studies vary in their methodological rigor (e.g., not all included a control group). Programs and interventions were assessed using a variety of quantitative methods (where qualitative findings were included, these are explored in Part 2 of this review¹⁶). The services and interventions examined ranged from those focused on: the family caregiver and their coping, knowledge and/or skills,^{34,35,56,119,120} sleep¹²¹ and respite,^{71,122} and bereavement⁹⁹; to those more broadly focused on patient care, such as specialized palliative care services¹¹⁰ and other forms of assistance to families,^{36,115,123} to those focused more on the patient^{98,124,125} (e.g., with the hope of spin-off benefits for family caregivers).

Some studies suggest that it may be possible, through particular services and programmes, to improve caregiver outcomes,¹¹⁰ family caregiver sleep quality, emotional wellbeing and caregiving confidence,^{35,56,121} comfort with caregiving, closure, and gain,⁹⁹ quality of life and caregiver task burden.^{120,125} Where programmes and interventions are assessed based on descriptive information or caregiver satisfaction, they usually demonstrate more positive outcomes (e.g., Clark et al.,¹²³ Kealey and McIntyre,¹²⁴ Kristjanson et al.,⁷¹ McLaughlin et al.³⁶). Where control groups are included and examined, however, there appears to be more difficulty demonstrating benefits in a range of outcomes and interventions,^{34,98,115,119} although qualitative benefits are often reported and some studies face methodological challenges. Further, even in the studies that show some positive changes, there are often no impacts in other indicators (Carter¹²¹ found no change in quality of life; McMillan et al.¹²⁰ found no change in caregiving mastery or coping).

Health care satisfaction. As noted, evaluations of services often rely on reports of caregiver satisfaction. Most generally, family caregivers who provide end of life care tend to report high satisfaction with in home services.^{27,42,57,88,113,126–129} However, satisfaction studies do not always conceptually or analytically distinguish between the caregiver's satisfaction with care

Table 4. Summary of intervention and evaluation studies

Intervention, program	Key results and caregiver outcomes
Studies with a control group	
FCG behavioural sleep intervention ¹²¹	Improved sleep quality and reduced depression; no difference from control group in terms of improvements in QOL. <i>n</i> = 30 (15 intervention; 15 controls)
Intervention to enhance patient QOL ⁹⁸	No impacts on caregiver QOL or burden (although there were improvements in patient QOL). <i>n</i> = 103 (49 intervention; 54 controls)
Hospice at Home services ¹¹⁵	No impact on FCG bereavement outcome. <i>n</i> = 96 (78 intervention; 18 controls)
FCG intervention: informal multi-professional teaching with facilitated peer exchange and support ¹¹⁹	No significant group differences for anxiety, depression and burden; multivariate tests disallowed due to attrition (<i>they suggest this is due to small sample size; note that qualitative benefits were reported</i>). <i>n</i> = 43 (36 intervention; 37 controls)
Standard hospice care plus three supportive visits to teach a coping skills intervention ¹²⁰	Improvements in FCG quality of life, perceived burden of patient symptoms, and caregiving task burden. However, there was no change in caregiving mastery, and either problem-focused or emotion-focused coping. <i>n</i> = 329 (109 for supportive visit intervention; 111 for three visits for coping skills intervention; 109 controls)
Transmural home care intervention (patient focus) to optimize cooperation and coordination between health care organizations ¹²⁵	Improvements to FCG quality of life, including into bereavement. <i>n</i> = 116 (79 intervention, 37 controls)
FCG intervention (increased support via weekly visits by a trained advisor) ³⁴	Non-significant differences in FCG health between intervention and control group; no differences in secondary outcomes, <i>although qualitative benefits were reported. Note: in an earlier study with five participants,¹⁵⁹ a telephone intervention, nurse-FCG teleconference, was implemented and decreased FCG depression, despair, disorganization was noted.</i> <i>n</i> = 271 (137 intervention; 134 control)
Studies without a control group	
Specialized palliative care services ¹¹⁰	Reduced unmet caregiver needs (short-term); assisted with bereavement adjustment (long-term). <i>n</i> = 949
FCG problem-solving intervention ³⁵	Improved FCG emotional tension, caregiving confidence, and positive problem-solving orientation. <i>n</i> = 34
'Macmillan carers schemes' (home-based practical and emotional help to cancer patients and families) ¹²³	Various descriptive findings (e.g., 70% of FCGs received help within 3 days of a request) and FCG satisfaction (70% rated service as important to them). <i>n</i> = 121
Group FCG psycho-educational programme focused on preparing FCGs for supporting relative with advanced cancer at home ⁵⁶	Significant improvements for outcomes such as preparedness, perceived competence, caregiving rewards, and having informational needs met. <i>Note: in an earlier study,⁵⁵ no intervention effects on such outcomes were noted with similar programme, although participants reported a more positive experience; that study used a control group.</i> <i>n</i> = 44 who completed all three time periods
Occupational therapy service for patients ¹²⁴	Satisfaction of FCGs was high as were reports of service accessibility and frequency; various descriptive data (e.g., 77% had no difficulty contacting the therapists) <i>n</i> = 30 patient-caregiver dyads
Community night respite palliative service ⁷¹	High FCG satisfaction with the service. <i>n</i> = 14
FCG programme focused on emotional, spiritual, and practical aspects of life; relationship completion and closure ⁹⁹	Improved FCG comfort with caregiving, closure, and caregiver gain. <i>n</i> = 926 who completed pre and post surveys
Hospice at Home service ³⁶	Bereaved FCGs reported high satisfaction, appreciated the service as helping them to provide home care, and rated staff highly in terms of knowledge, courteousness, and approachability. Qualitative benefits also reported. <i>n</i> = 128
Respite services ¹²²	Mixed effects for FCG stress outcomes (some positive change, some negative, some no change). The authors speculate this may be a methodological issue. Qualitative benefits were reported. <i>n</i> = 25

FCG, family caregiver; QOL, quality of life.

provided to the patient, and care provided to them as a caregiver to support them in their role. While some articles focus solely or primarily on family caregiver satisfaction with patient care,^{78,130} and some on professional support provided to the caregiver,^{42,123,131} the majority measure satisfaction with both aspects of formal support.^{27,57,67,109,115,116,124,125,127,128,132,133} Caregivers are in fact often in a 'dual role' as providers of informal care to the patient, and clients or recipients of support from community-based service organizations (e.g., Aoun et al.¹³⁴); they can in this respect be viewed as part of the unit of care. Satisfaction with both aspects of care is important. In fact, Brazil et al.¹³² note that of the services deemed most valuable by family caregivers, three were focused on the care recipient (in home nursing care, family doctors, and medical specialists) and two were caregiver oriented (housekeeping and religious support).

Features of care identified as particularly important and/or not adequately addressed in some situations include: meeting psychosocial and spiritual needs;⁶⁶ symptom management, including pain;^{27,126} staff availability and accessibility;²⁷ the adequacy of help, including for instance with transportation and bathing¹²⁶ and respite;⁶⁶ bereavement services;¹²⁷ and communication/information.^{66,126,133}

Many satisfaction studies were excluded from this review because they were based on the views of family members that were not identified as caregivers. However, there has been no study that we could identify that seeks to examine whether and how the caregiving experience might impact satisfaction with services at the end of life (for instance, there were no comparisons between caregiving and non-caregiving family members). In addition, it is often difficult to interpret descriptive ratings of service satisfaction as 'high' or 'low', given that it is rare that scores are discussed in relation to satisfaction score comparators or existing norms. An exception is Young et al.,⁶⁷ who report that 51% of family caregivers rated health services as excellent or good, comparing this to a 38% rating in the same sample for social services.

Several researchers have also sought to identify correlates and predictors of family caregiver satisfaction with formal services (only one of these studies, identified below, is longitudinal, and thus caution is required in causal interpretations). While satisfaction with *overall* care was not associated with site of death in one study,¹⁰⁹ caregivers of patients who died at home reported less satisfaction with particular aspects of care such as communication and emotional support. LeCouturier et al.¹³³ noted that care setting and type may be important: hospital care was the lowest rated (high dissatisfaction) and care from hospice and specialist nurses the most highly rated.

Features of formal services may also be important. In a study by Kristjanson et al.,⁸⁹ caregivers who received more tailored services and more palliative care services were more satisfied. Several service factors were also identified by LeCouturier et al.,¹³³ most notably the frequency and timing of visits, specialist versus generic services, and level of support. Medigovich et al.¹²⁷ conclude that the best predictor of satisfaction is care perceptions (i.e., the family caregiver's understanding about patient care).

Various patient and caregiver characteristics may also be associated with satisfaction. For example, disease condition may be important (e.g., through differences in available services for patients and families with particular conditions): caregivers to those with motor neurone disease and Parkinson's, in contrast to other neurodegenerative conditions, expressed higher satisfaction in two studies (Kristjanson et al.^{66,89}); and caregivers of patients with renal disease in another study had lower ratings of home hospice services.⁵⁷ Higher satisfaction with formal services has been associated with caregivers being retired,⁵⁷ unmarried,⁵⁷ depressed (Fleming et al.¹³⁰ and a longitudinal study by Nolen-Hoeksma et al.¹²⁸), older,¹²⁷ and in one study being female⁵⁷ and in a longitudinal study being male.¹²⁸ Caregivers who perceived their social activities were more restricted as a result of caring expressed more satisfaction with general practitioner care.⁷⁸

Health care services use. While some descriptive information about utilization and access to services is included in the more general needs assessment studies, research examining service use as a core focus was rarer. Various studies tend to identify relatively low rates of use of services that are directed at family caregivers.^{23,41,65,87,103} There were only a few studies examining predictors of service use. Adams et al.¹³⁵ associated lower rates of service use among hospice clients with having a child or spouse primary caregiver (compared to paid or extended family) and Grande et al.¹³⁶ identified that older caregiver age was associated with more limited access to home-based palliative care service. Caregiver use of bereavement services has been associated in one longitudinal study with being a spouse or younger caregiver, having depression, witnessing highly distressing death events, providing higher levels of assistance with instrumental activities of daily living during caregiving, greater availability of instrumental support for the caregiver, and physician communication with the caregiver about prognosis prior to death.²³ Predictors of mental health service use identified by Vanderwerker et al.¹³⁷ include having discussed mental health concerns before or after the patient's diagnosis, but did not include meeting the criteria for psychiatric disorder.

Discussion

This study was motivated by our desire to understand the current, and increasingly home-based, context of palliative care and family caregiving. Our goal was to summarize existing quantitative research on home-based family caregiving for those with terminal conditions. While acknowledging that this was not a systematic review, our comprehensive overview of the state of recent contributions of quantitative research to the understanding of home-based family caregiving at end of life provides some important methodological guidance and directions for further research in this area.

Although we did not apply systematic methodological criteria, our general observation considering the research as a whole suggests it is methodologically limited. There is need for caution in generalizing, interpreting, and applying the findings discussed here. For instance, samples tend to be based on convenience samples of volunteers recruited through formal service providers (e.g., non-random). Further, the large proportion of cross-sectional research renders our ability to interpret causal direction problematic (i.e., there may be reciprocal causal pathways between independent and dependent variables). Lastly, sample sizes tend to be relatively small and approximately half of the studies used only descriptive and/or bivariate methods of analysis (see Table 1).

The lack of specificity and consensus in key definitions such as 'family caregiver', 'end of life', and 'need' makes it difficult to compare studies and likely contributes to some of the contradictory and diverse findings identified in this review. This problem is not unique to this area of research (e.g., Lamb et al.,¹³⁸ Hauer et al.¹³⁹). The solution requires the identification of a series of consensual definitions to guide future research and facilitate comparison, as well as the observation of a series of reporting conventions which ensure sufficient information is reported (e.g., see guidelines created in Moher et al.¹⁴⁰ and Simera et al.¹⁴¹). In Table 5 we present definitions of terms which proved problematic in undertaking this review, which we propose could be used in future research.

The identification of the setting of care also tends to be problematic; many studies did not specify setting – and indeed, the term 'hospice' is often used to refer to a combination of facility-based as well as home-based services. Other studies included caregivers of patients that transitioned between home and institution or recruited from both in-patient and outpatient studies without providing distinguishing details. More explicit attention to care setting is needed, including distinguishing findings between at-home and facility-based care experiences. However, some of this difficulty may

simply reflect the realities of family caregiving at the end of life and the situations and changes involved in the role (i.e., that transitions between settings are common, including brief periods of hospitalization). The extent to which family caregiving at end of life 'differs' depending on the setting and, thus, the relevance of facility-specific findings for informing our understanding of home-based caregiving at end of life requires further investigation.

We further identified a lack of theoretical or conceptual frameworks to guide analyses or variable selection. Brazil et al.¹⁴² also highlights the importance of theory for enhancing understanding of the complexity of implementation and intervention effects. Existing conceptual models tend to be psychological in nature, focusing on individual characteristics (e.g., patient and caregiver), caregiving stressors (e.g., patient symptoms), and caregiver coping and appraisal to explain caregiver outcomes. A few studies include variables measuring features of organizational, cultural, economic, or political contexts; overall, however, a multi-level understanding of contextual influences on outcomes for family members providing palliative care is lacking.

There is a dearth of systematic or comprehensive approaches to the quantitative assessment of need among family members providing palliative care and a tendency to present generalized findings implying that all caregivers have common needs, despite evidence⁷⁰ that suggests that individualized and flexible approaches to assessing needs may be more appropriate than blanket interventions. Questions requiring further exploration include: are the needs of patients and family caregivers differentiated by both caregivers and policy-makers? What factors influence whether family caregivers are able to articulate their needs? To what extent are needs assessed relative to the needs of family caregivers and/or patients, and to available resources? More broadly, how can generalized understandings of needs be reconciled with the individualized understandings (e.g., at the practice level)?

Various factors that can affect caregiver outcomes were identified in the studies we reviewed, including patient characteristics, disease type, patient health, function and distress, characteristics of caregiving situations (such as setting and intensity of care provided, although findings are mixed), caregiver coping and appraisals, and caregiver characteristics. Findings are not always consistent. As well as the problem of definition, this may be explained in part because different measures, outcomes and patient populations are used. It is also noteworthy that explanations for causal pathways are often lacking. For instance, explanations for age differences are not well explored and are

Table 5. Proposed Definitions for Use in Research on Family Caregiving at End of Life

Term	Proposed definition
Caregiving	Assistance provided to individuals who are ‘in need of support because of ‘a disability, mental illness, chronic condition, terminal illness or who are frail’. ¹⁸¹ This can include ‘attention to any of the needs of the person, including hands on care, overnight care, respite, shopping, collection of medications, taking to appointments, emotional support, bathing, etc.’ ¹¹⁰ Caregiving is distinguished from ‘normal helping’ that occurs in the context of family relationships; rather, caregiving emerges because of particular needs for assistance. ¹⁴
Family caregivers at end of life	Individuals who provide any physical, emotional, and instrumental support and assistance to individuals with life-limiting illness that they view as family members. These family caregivers are not acting in a professional or occupational capacity. They may or may not be co-residing with the care recipient and the care recipient may be in either a home or institutional setting.
Palliative care	An approach to formal service provision ‘that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.’ ¹⁸² Palliative care: provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patients illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; will enhance quality of life and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.
End of life care	‘End of life care helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.’ This definition includes palliative, hospice, generalist, and specialist end of life care services and specific services and complex interventions offered to people with advanced, progressive, or incurable illness and their families, caregivers, or significant others during care and bereavement. ¹⁴
Home-based care	Refers to the location of where care is occurring, in this case the patient’s or family member’s home. In home-based care, family caregivers often feel responsible for most aspects of care even if receiving formal hospice and palliative home care services.
Inpatient/institutional care	Refers to the location of where care is occurring: in this case, an inpatient, acute, chronic, or long-term care health care facility and, in some jurisdictions, free-standing hospice facilities. In institutional settings, legal responsibility for care is largely transferred to professional carers, although the family caregiver often continues to provide large amounts of care.
Caregiver needs	Specific indicators of negative caregiver outcomes, such as physical and mental morbidity and burden, which require intervention because the population level is above that generally accepted within a particular society and for which family caregivers can benefit from intervention (drawing on/adapting the epidemiological definition cited in Franks et al., ¹⁸³ Last, ¹⁸⁴ and Stevens and Gillam ¹⁸⁵). While user definitions of support needs, such as the perceived requirement or wish for support and care from health professionals, ¹⁸⁶ are not encompassed in this definition, we acknowledge that caregivers themselves may define ‘need’ differently.

complicated by relationship type. There could also be more longitudinal research and/or investigation into possible buffers, mediators, and interaction effects. Factors influencing bereavement outcomes in particular still remain to be fully explicated.

Findings from several studies suggest it may be possible, through particular services, to improve some caregiver outcomes, although where programmes are assessed based on descriptive information or caregiver satisfaction, they usually fare better; where control

groups are included, there may be more difficulty demonstrating positive outcomes (despite reported qualitative benefits).

Echoing findings from the majority of more general studies of patient and family satisfaction with health care^{143–145} and family member (but not family caregiver) satisfaction with end of life care,^{146–148} studies in this review identified fairly high satisfaction. Whether and how the caregiving experience might impact satisfaction (e.g., comparisons between caregiving and non-caregiving family) is unknown. Research into predictors of family caregiver satisfaction with formal services demonstrate mixed findings, but in general, suggest that site of death/care setting and other organizational and relational features of formal services may be important, as well as perceptions about patient care and patient and family caregiver characteristics.

Future empirical study should consider how and whether providing care for a dying family member differs from providing care for a chronically ill family member or from the experience of family members who are not providing care, as well as the extent to which caregiver outcomes persist over time/into bereavement. Further, while health care service use by family caregivers appears generally to be low, there are few studies of the predictors and influences of access and/or utilization of services. Lastly, the majority of studies focus on palliative care for cancer patients, suggesting a potential gap in knowledge with regards to caregiving for those with other conditions.

In conclusion, social and demographic changes over the last several decades (aging population, declining fertility, increased female labour force participation and divorce/separation, shifts from facility to community care) have raised concerns among policy-makers regarding the future availability of informal family caregivers.² In this review, we identified a number of important gaps for future conceptual development and empirical research. Such work is crucial to enhance our knowledge base and, ultimately, to develop appropriate health care policies, services, and interventions to effectively support family members providing end of life care in their increasingly important, but often under-recognized role.

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