

# Palliative Care for Family Caregivers

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Family caregivers provide substantial care for patients with advanced cancer, while suffering from hidden morbidity and unmet needs. The objectives of this review were to examine risk factors associated with caregiving for patients with advanced cancer, evaluate the evidence for pertinent interventions, and provide a practical framework for palliative care of caregivers in oncology settings. We reviewed studies examining the association of factors at the level of the caregiver, patient, caregiver-patient relationship, and caregiving itself, with adverse outcomes. In addition, we reviewed randomized controlled trials of interventions targeting the caregiver, the caregiver-patient dyad, or the patient and their family. Risk factors for adverse mental health outcomes included those related to the patient's declining status, symptom distress, and poor prognostic understanding; risk factors for adverse bereavement outcomes included unfavorable circumstances of the patient's death. Among the 16 randomized trials, the most promising results showed improvement of depression resulting from early palliative care interventions; results for quality of life were generally nonsignificant or showed an effect only on some subscales. Caregiving outcomes included burden, appraisal, and competence, among others, and showed mixed findings. Only three trials measured bereavement outcomes, with mostly nonsignificant results. On the basis of existent literature and our clinical experience, we propose the CARES framework to guide care for caregivers in oncology settings: Considering caregivers as part of the unit of care, Assessing the caregiver's situation and needs, Referring to appropriate services and resources, Educating about practical aspects of caregiving, and Supporting caregivers through bereavement. Additional trials are needed that are powered specifically for caregiver outcomes, use measures validated for advanced cancer caregivers, and test real-world interventions.

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## INTRODUCTION

Family caregivers are partners, relatives, or friends who provide care that requires substantial time over months to years and involves performing a wide range of physically, socially, emotionally, or financially demanding tasks.<sup>1,2</sup> More than 40 million adults in the United States serve as family caregivers, and cancer is among the top five reasons for which a caregiver is required.<sup>3</sup> Caregiving tasks are increasingly complex, particularly in advanced disease settings, and include assistance with activities of daily living, coordinating and attending hospital appointments, managing and providing medical care at home, and assisting with decision making.<sup>4</sup> For patients with advanced cancer, caregivers' cost of providing this care is estimated at more than \$US 35,000 yearly; this includes only time costs and excludes lost income from giving up employment or direct medical costs associated with cancer care.<sup>5</sup>

Modern medicine has tended to prioritize the rights and interests of patients, emphasizing patient

autonomy and confidentiality.<sup>6</sup> Although this approach has undoubtedly benefited patients, for caregivers it has resulted in unmet informational needs and hidden morbidity.<sup>7-10</sup> An exception to this patient-centered approach is palliative care, which emphasizes family-centered care and improvement of outcomes for caregivers as well as patients.<sup>11</sup> A family-centered palliative care approach within oncology may lead to improved support for caregivers of patients with advanced cancer.

In this article, we review the literature regarding palliative care for family caregivers of patients with advanced cancer. Palliative care is defined as care that aims to improve the quality of life of patients and their families facing life-threatening illness<sup>11</sup>; advanced cancer is defined as cancer that is metastatic or life-limiting.<sup>12</sup> We describe characteristics of caregivers in advanced cancer settings, discuss the impact of caregiving on this group, identify risk factors associated with adverse outcomes, and review potential interventions. On the basis of this literature, we provide

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a practical framework to guide palliative care for family caregivers.

## CHARACTERISTICS OF CAREGIVERS AND IMPACT OF CAREGIVING

Caregivers for patients with advanced cancer are most often female, are the spouse or adult child of the patient, and have a mean age of approximately 50 to 65 years.<sup>4,13,14</sup> Compared with caregivers for other patient populations with late-stage disease, they tend to care for patients who are younger<sup>1,14</sup> and provide more intense care (> 20 hours per week) over shorter periods of time (months to < 3 years rather than > 3 years).<sup>14</sup> The time spent performing caregiving duties ranges from a few hours per week to 17 hours daily.<sup>4,13,14</sup> Up to half of caregivers providing care for patients with advanced cancer continue to work, but many need to reduce their work hours or stop working.<sup>13,15,16</sup> This can result in long-term repercussions, including challenges returning to the workforce and loss of retirement savings.<sup>1</sup>

Compared with noncancer caregivers, caregivers of patients with cancer may experience greater financial burden associated with caregiving, particularly for out-of-pocket expenses, including prescription drugs.<sup>14,15</sup> Cancer treatment has been shown to be associated with 3.1 additional hours weekly of caregiver input, corresponding to an average annual cost of \$US 1,200 per patient.<sup>17</sup> Caregiving time costs are related to cancer type and stage; higher time costs are associated with lung and GI compared with breast or prostate cancer and with metastatic compared with early-stage disease.<sup>5</sup>

Although caregiving can be associated with positive outcomes, including post-traumatic growth, a sense of enhanced personal strength, and a closer spousal relationship,<sup>18-20</sup> there may also be negative physical and psychological consequences. Sleep disturbance, weight loss, and fatigue are commonly reported,<sup>4,21</sup> and the psychological impact of caregiving can be profound. The overall mental health of caregivers of patients with advanced cancer is equivalent to less than the 30th percentile for the general US population,<sup>13,22</sup> with an increased incidence of both major depressive episodes and generalized anxiety disorder.<sup>23</sup> Caregivers' distress may exceed that of the patients they care for<sup>10,15,24</sup> and is particularly pronounced at later stages of disease.<sup>25,26</sup> The prevalence of significant anxiety in caregivers of patients at advanced stages of illness is approximately 40% to 42%,<sup>15,16,24</sup> compared with 27% to 28% among patients.<sup>15,24</sup> Rates of depression in caregivers are reported to be from 16% to 67%,<sup>10,15,24,27-31</sup> increasing as the patient's death approaches.<sup>15,27,30</sup>

## RISK FACTORS FOR ADVERSE OUTCOMES OF CAREGIVING

Risk factors for adverse outcomes of caregiving in advanced cancer settings can be divided into factors at the

level of the caregiver, patient, caregiver-patient relationship, and caregiving itself (Table 1). Risk factors for depression are the most well-documented. At the level of the caregiver, these risk factors include female sex,<sup>27-29</sup> younger age,<sup>35</sup> financial difficulties,<sup>28</sup> and lack of social support.<sup>30,38</sup> Among patient-related factors, younger age,<sup>30,40</sup> advancing illness,<sup>27,28</sup> poor well-being<sup>30</sup> and performance status,<sup>29</sup> and poor prognostic understanding<sup>24</sup> are all associated with depression. Relational factors, including a spousal relationship,<sup>28-30,35</sup> insecure caregiver attachment style (represented by significant levels of abandonment anxiety and interpersonal avoidance within an intimate relationship),<sup>10,31,43</sup> and family conflict, are also associated with a greater risk for depression.<sup>35</sup> Finally, risk factors for depression related to caregiving include caregiver burden,<sup>10,15,28-30</sup> lack of confidence in caregiving,<sup>30</sup> and greater hours spent providing care.<sup>13</sup> Risk factors for general mental health, anxiety, caregiver burden, physical health, and quality of life have also been described and are listed in Table 1. Of note, older caregiver age is associated with worse physical well-being, whereas younger caregiver age is associated with worse psychological well-being.

It is also important to consider factors that may affect bereavement (Table 2). In particular, lack of preparation for the patient's death,<sup>26,44,45,49</sup> negative perception of the patient's death,<sup>45</sup> a hospital death,<sup>41</sup> and hospice enrollment shorter than 3 days<sup>48</sup> may all contribute to increased bereavement morbidity for the family caregiver.

## RANDOMIZED CONTROLLED TRIALS OF INTERVENTIONS FOR FAMILY CAREGIVERS

Interventions for caregivers of patients with advanced cancer can be divided into three categories, according to whether the target of the intervention is the caregiver, the caregiver-patient dyad, or the patient and their family. The first two categories are composed of interventions delivered to a group or on an individual level; these interventions have a primary focus on psychoeducational aspects (managing symptoms, practical aspects of care, and the caregiver-patient relationship), skills training (coping, communication, and problem-solving), and therapeutic counseling (development of a therapeutic relationship to address concerns related to cancer or caregiving).<sup>51</sup> The third category encompasses palliative care team interventions in outpatient, inpatient, or home settings. The palliative care interventions were focused primarily on the patient but also included the family as recipients of care.

The main outcomes that have been measured in studies of these interventions are quality of life, mental health, and outcomes related to caregiving. Quality of life has been measured both using generic measures, such as the 36-Item Short Form Health Survey,<sup>52</sup> or using measures developed and validated specifically for caregivers, such as the Caregiver Quality of Life Index–Cancer.<sup>53</sup> Mental health

**TABLE 1.** Risk Factors for Adverse Outcomes of Caregiving in Advanced Cancer

Risk Factor	Potential Impact on Caregiver	
	Mental Health	Physical Health, Quality of Life, Burden
Caregiver-related factors		
Female	Worse mental health, psychological distress, <sup>9,13,28,32</sup> depression, <sup>27-29</sup> anxiety <sup>27</sup>	Increased burden <sup>33</sup>
Younger	Worse mental health, psychological distress, <sup>22,32,34</sup> depression <sup>35</sup>	
Older		Worse physical health <sup>9,22</sup>
Lower education	Increased depression <sup>28</sup>	Worse physical health <sup>22</sup>
Financial difficulties, unemployment	Increased depression <sup>28</sup>	Worse quality of life, <sup>36</sup> increased burden <sup>37</sup>
Less social support	Worse psychological distress, <sup>22,32</sup> depression <sup>30,38</sup>	Increased burden <sup>38,37</sup>
Working outside caregiving duties		Increased burden <sup>33,39</sup>
Patient-related factors		
Younger age	Increased depression <sup>30,40</sup>	Worse quality of life <sup>41</sup>
Worse physical well-being, poor performance status, more advanced disease	Increased depression, <sup>27-30</sup> anxiety <sup>15,27</sup>	Worse quality of life, <sup>13,42</sup> increased burden <sup>39</sup>
Increased symptom distress	Worse psychological distress, <sup>32</sup> depression <sup>30</sup>	Increased burden <sup>37</sup>
Worse emotional well-being	Worse mental health <sup>13,22</sup>	
Worse social well-being		Worse physical health <sup>22</sup>
Poor prognostic understanding	Increased depression <sup>24</sup>	
Relational factors		
Spousal relationship	Worse mental health, <sup>22</sup> depression <sup>28-30,32</sup>	Increased burden <sup>37</sup>
Family conflict	Increased depression <sup>35</sup>	
Caregiver's anxious or avoidant attachment	Increased depression <sup>10,31</sup>	
Caregiving-related factors		
Caregiver burden	Worse psychological distress, <sup>32</sup> depression, <sup>10,15,28-30</sup> anxiety <sup>15</sup>	Worse quality of life <sup>42</sup>
Poor confidence in caregiving	Increased depression <sup>30</sup>	Worse quality of life, <sup>42</sup> increased burden <sup>37</sup>
Care for other dependents		Worse quality of life <sup>13</sup>
Hours spent caregiving	Worse mental health <sup>13</sup>	

has been quantified using validated measures for depression and anxiety or using the mental health subscale of quality-of-life measures.<sup>52</sup> The most commonly measured outcome related to caregiving is caregiver burden, a multidimensional construct that originated in the geriatric literature.<sup>54</sup> Caregiver burden encompasses the extent to which caregiving has had an adverse effect on the caregiver's emotional, social, financial, physical, and spiritual functioning and has been conceptualized both as a trial end point and as an important contributor to anxiety and depression.<sup>10,15,29</sup>

We reviewed randomized controlled trials published since 2005, reporting on quality of life, mental health, and caregiving outcomes for caregivers of patients with advanced cancer. Trials with outcomes for caregivers completed before 2005 assessed mainly palliative care team interventions and have been reported on in previous reviews,<sup>55,56</sup> as have outcomes for interventions in earlier

stages of cancer.<sup>51,57</sup> We also excluded pilot trials and small trials with fewer than 50 participants. Two systematic reviews, both published in 2011, have assessed interventions for caregivers of patients with advanced cancer<sup>4,58</sup>; however, nine out of 15 studies reviewed here, including four out of five of those assessing palliative care team interventions, were published since those reviews and were therefore not previously included.

There were mixed results across studies and interventions (Table 3). The most consistently favorable results were for depression, particularly for caregivers participating in early palliative care interventions. Specifically, there were positive results for depression in a trial of early versus delayed palliative care, where caregivers of patients in the intervention group received three additional structured weekly telephone coaching sessions, monthly follow-up, and a bereavement call.<sup>73</sup> Results for caregivers' depression also favored the intervention group in a trial of early

**TABLE 2.** Factors Affecting Bereavement Outcomes

Factor	Bereavement Outcome
Caregiver-related factors	
Less social support	Depression, <sup>44</sup> prolonged grief <sup>45</sup>
Lower socioeconomic status	Worse grief <sup>41</sup>
Less education	Depression, worse grief, complicated grief <sup>46</sup>
Pre-loss depression	Depression, <sup>44,46</sup> worse grief, complicated grief, <sup>46</sup> prolonged grief <sup>45</sup>
Patient-related factors	
Young patient age	Worse grief, complicated grief <sup>46</sup>
Hospital death	Worse grief, <sup>41</sup> prolonged grief <sup>47</sup>
Negative perception of patient's death	Prolonged grief <sup>45</sup>
Shorter hospice enrollment	Increased depression <sup>48</sup>
Lack of preparation for death	Depression, <sup>44,49</sup> prolonged grief <sup>45,49</sup>
Relational factors	
Close relationship to patient	Worse grief <sup>41</sup>
Spousal relationship to patient	Prolonged grief <sup>50</sup>
Poor family functioning	Prolonged grief <sup>50</sup>
Caregiving-related factors	
Caregiver burden	Depression <sup>44</sup>
Stopping work during caregiving	Worse grief <sup>41</sup>

outpatient palliative care for patients with advanced lung or noncolorectal GI cancers<sup>70</sup> and for one of two measures of depression in a trial of early inpatient palliative care for patients undergoing hematopoietic stem-cell transplantation.<sup>72</sup> Two interventions directed at patient-caregiver dyads,<sup>66,68</sup> one of which used an online intervention,<sup>66</sup> also had positive results for general measures of mental health and mood.

Most trials across all three categories of interventions assessed quality-of-life outcomes, but results were generally nonsignificant, both for caregiver-specific and non-specific quality-of-life measures. Results favored the intervention group for only one trial where the intervention was directed at the caregiver alone<sup>64</sup> and one where the intervention was directed at the patient-caregiver dyad.<sup>68</sup> Other trials had positive results for some aspects of quality of life but not others. For example, inpatient early palliative care for patients undergoing hematopoietic stem-cell transplantation led to improvement in only administrative and financial domains of quality of life,<sup>72</sup> whereas patient-caregiver dyads who received nursing home visits and phone sessions had improved social and emotional, but not functional and physical, quality of life relative to controls.<sup>67</sup>

Studies used a wide variety of caregiving outcomes and subscales, including perceived burden, appraisal, coping, strain, preparedness, competence, self-efficacy, and rewards of caregiving. These tended to have mixed findings among outcomes or subscales. Where results for burden favored the intervention group, there tended to be a concomitant positive effect on either quality of life<sup>64</sup> or mental

health,<sup>66,73</sup> supporting research indicating an association with these outcomes.<sup>10,15,28-30,32,42</sup>

Of note, only three trials specifically measured bereavement outcomes in caregivers, with mostly nonsignificant results.<sup>61,63,76</sup> A third recruited caregivers of patients with late-stage disease, such that 70% of caregivers were bereaved at the time of analysis; there were improvements in anxiety immediately after the group therapy intervention and in depression at 12 months.<sup>60</sup>

A number of challenges were evident related to conducting clinical trials with caregivers of patients with advanced disease. This area of research is still in an early stage of development, and more work needs to be done before there are interventions that are ready for widespread dissemination and implementation. All trials had methodological limitations, including low recruitment and high attrition rates of overtaxed caregivers. In addition, trials of palliative care interventions tended to focus on patient outcomes and to be underpowered to detect effects for caregivers. The level of attrition and resultant lack of power were especially problematic for bereavement outcomes. Control groups were often not well described, and it was unclear to which services participants routinely had access. Studies often had numerous or unspecified primary end points and used a large variety of measures, particularly for caregiving outcomes. Although caregiver-specific quality-of-life measures have been developed, these were no more likely to yield positive outcomes than nonspecific measures. This may be because they lack items specifically related to caring for patients who are seriously ill<sup>18</sup>; additional

**TABLE 3.** Randomized Controlled Trials Assessing Outcomes for Caregivers of Patients With Advanced Cancer

First Author	Setting	Population	Intervention	Quality of Life	Mental Health	Caregiving	Other
Interventions directed at the caregiver alone							
Holm <sup>59</sup>	Community palliative care, Sweden	270 CGs, advanced cancer	Three manualized multidisciplinary group sessions	NS (nonspecific measure)	NS (depression, anxiety)	MF <sup>a</sup>	
Fegg <sup>60</sup>	Inpatient palliative care, radiation, Germany	160 CGs, 81% advanced cancer, 19% noncancer	Six existential behavioral therapy group sessions	MF (nonspecific measures) <sup>b</sup>	MF (depression, anxiety) <sup>b</sup>	NM	NS (somatization)
Hudson <sup>61,62</sup>	Community palliative care, Australia	298 CGs, advanced cancer	Nursing assessment of needs, guidebook, care planning	NM	NS (distress) <sup>c</sup>	MF <sup>c</sup>	MF (bereavement distress) <sup>c</sup>
Walsh <sup>63</sup>	Community palliative care, United Kingdom	271 CGs, advanced cancer	Nurses and social workers providing advice and support	NS (nonspecific and specific)	NS (distress)	NS (strain)	NS (satisfaction, grief)
McMillan <sup>64</sup>	Community-based hospice, United States	329 CGs, advanced cancer	Three nursing visits to teach coping skills	FI (CG-specific measure)	NM	MF <sup>d</sup>	
Hudson <sup>65</sup>	Community palliative care, Australia	106 CGs, advanced cancer	Two nursing home visits, phone call, guidebook, audiotapes	NM	NS (anxiety)	NS <sup>e</sup>	
Interventions directed at patient-caregiver dyads							
DuBenske <sup>66</sup>	Four cancer centers, United States	285 dyads, advanced lung cancer	Online information, communication, and coaching	NM	FI (mood)	MF <sup>f</sup>	
Northouse <sup>67</sup>	Four cancer centers, United States	484 dyads, advanced cancer	Nursing home visits and phone sessions	MF (nonspecific measure) <sup>g</sup>	NM	MF <sup>g</sup>	
Northouse <sup>68</sup>	Three cancer centers, United States	263 dyads, prostate cancer	Three nursing home visits and two phone sessions	FI (nonspecific measure) <sup>h</sup>	FI (mental health, 4 months) <sup>h</sup>	MF <sup>h</sup>	
Northouse <sup>69</sup>	Four cancer centers, United States	182 dyads, recurrent breast cancer	Nursing home visits and phone sessions	NS (CG-specific measure)	NS (mental health)	MF <sup>i</sup>	NS (uncertainty, hopelessness)
Interventions directed at the patient and their family							
El-Jawahri <sup>70</sup>	Outpatient clinics, cancer center, United States	275 CGs, advanced noncolorectal GI or lung cancer	Early PC addressing needs of patients and caregivers	NS (nonspecific measure)	FI (distress, depression at 12 weeks) <sup>j</sup>	NM	
(continued on following page)							



TABLE 3. Randomized Controlled Trials Assessing Outcomes for Caregivers of Patients With Advanced Cancer (continued)

First Author	Setting	Population	Intervention	Quality of Life	Mental Health	Caregiving	Other
McDonald <sup>71</sup>	Outpatient clinics, cancer center, Canada	182 CGs, advanced cancer	Early PC addressing needs of patients and caregivers	NS (nonspecific and specific)	NM	NM	FI (satisfaction with care)
El-Jawahri <sup>72</sup>	Inpatient tertiary care hospital, United States	94 CGs, inpatients receiving HCT	Early PC with focus on managing patient's symptoms	MF (CG-specific measure) <sup>a</sup>	MF (depression, anxiety) <sup>a</sup>	NM	FI (coping)
Dionne-Odom <sup>73</sup>	Approximately 50% rural, 50% urban, United States	122 CGs, advanced cancer	Early PC, including telephone coaching sessions with advanced practice nurse <sup>d</sup>	NS (CG-specific measure)	FI (depression)	MF <sup>m</sup>	NS (post-bereavement depression, grief)
O'Hara <sup>74</sup>	Approximately 50% rural, 50% urban, United States	198 CGs, advanced cancer	Patient-focused early PC; nurse-led phone education sessions	NM	NM	NS (burden)	
Clark <sup>75</sup>	Radiation therapy clinic, United States	83 CGs, cancer, palliative radiation	Eight-session multidisciplinary intervention (patients)	NS (nonspecific measure)	NM	NS (burden)	

Abbreviations: CG, caregiver; FI, results overall favor the intervention group; HADS-A, Hospital Anxiety and Depression Scale - Anxiety Subscale; HADS-D, Hospital Anxiety and Depression Scale - Depression Subscale; HCT, hematopoietic stem-cell transplantation; MF, mixed findings: results statistically significant for some measures or end points but not others; NM, not measured in this trial; NS, not statistically significant; PC, palliative care; PHQ-9, Patient Health Questionnaire - 9 items; QOL, quality of life.

<sup>a</sup>Increased preparedness for caregiving (primary end point) both postintervention and at 2 months; increased self-perceived competence at 3 weeks; nonsignificant results for rewards of caregiving, caregiver burden.

<sup>b</sup>Significant results favoring intervention for anxiety and QOL post-treatment and for depression at 12 but not 3 months; primary end point not specified.

<sup>c</sup>No difference in distress (primary outcome) postintervention; improved preparedness and competence for 2-visit intervention group; no reduction in unmet needs or improvements in positive aspects of caregiving. Distress post-bereavement reduced in the one-visit intervention group, but not in the two-visit group.

<sup>d</sup>At 30 days, results were positive for caregiving burden but not caregiving mastery or coping.

<sup>e</sup>Nonsignificant caregiving outcomes included preparedness, confidence, rewards of caregiving, self-efficacy.

<sup>f</sup>Results favored intervention at 6 months for burden but not disruptiveness.

<sup>g</sup>Improvement in social and emotional, but not functional and physical, QOL; caregiving results favored intervention for coping and self-efficacy, but not appraisal or interpersonal relationships.

<sup>h</sup>Results for QOL and mental health favored intervention at 4 months but not 8 or 12 months; caregiving results favored intervention for appraisal (4 months), self-efficacy (4 and 12 months), communication with patients (all time points); active coping favored intervention at 12 months only; avoidant coping NS at all time points. Primary end point not specified.

<sup>i</sup>Results favored intervention for appraisal, but not coping, at 3 months; no significant results at 6 months.

<sup>j</sup>Results favored intervention for distress and depression, but not anxiety, at 12 weeks; no differences at 24 weeks; terminal decline showed intervention effects on distress, anxiety, and depression at 3 and 6 months before patient death.

<sup>k</sup>No difference in overall QOL but improvement in administrative and financial domains of QOL at 2 weeks; lower depression scores at 2 weeks (HADS-D, but not PHQ-9 measure); no difference in anxiety (HADS-A).

<sup>l</sup>Caregivers in the intervention group for this trial received an early palliative care intervention directed at the patient and their family, which also included a caregiver-specific component.

<sup>m</sup>Results favored intervention for stress burden but not objective or demand burden.

research is required to update these measures or to develop ones that are more responsive in palliative care settings.

## RECOMMENDATIONS FOR CAREGIVER ASSESSMENT AND SUPPORT

On the basis of the literature presented, previous reviews,<sup>2,34,57,77,78</sup> and our clinical experience, we have developed a framework to address the needs of family caregivers in a time-limited oncology setting. This framework is grounded in the core principles of palliative care, which include support for family members during the patient's illness and in their own bereavement.<sup>11</sup> The CARES framework is currently in use at the Oncology Palliative Care Clinic at the Princess Margaret Cancer Centre, where there is an emphasis on early integrated palliative care intervention and collaborative care between oncologists and palliative care providers.<sup>79</sup> Table 4 summarizes components of the CARES framework, which is described in the current section.

### Consider Caregivers as Part of the Unit of Care

Family caregivers should be considered not only part of the patient's care team but also part of the unit of care. This

includes recognizing their important role, respecting their opinion, and inquiring about their well-being, which is often related to that of the patient.<sup>27-30</sup> Most patients prefer to participate actively in decision making, but others may wish to defer decisions to their caregiver.<sup>80</sup> These preferences need to be established and documented. Caregivers are a valuable source of information about the patient's status, and their input may be important for planning treatment. Their requests for private communication with the physician should be respected; relevant health care information may be shared with the family caregiver provided that the patient agrees to this.<sup>6</sup>

### Assess the Caregiver's Situation, Perceptions, and Needs

The caregiver should be assessed together with the patient and, ideally, also separately.<sup>6</sup> The assessment may be provided by a nurse or social worker,<sup>78</sup> but knowledge of this assessment is also important for the physician, because it can influence care not only for the caregiver but also for the patient. Question prompt lists may help caregivers to ask relevant questions about their own needs, while also stimulating discussion about prognosis and end-of-life issues.<sup>81</sup>

**TABLE 4.** The CARES Framework for Family Caregivers

Domain	Description
Consider caregivers as part of the unit of care	Consider caregivers as part of the unit of care as well as part of the care team
	Acknowledge the importance of the caregiving role
	Respect the patient's wishes regarding the nature and degree of caregiver participation in decision making
Assess the caregiver's situation, perceptions, and needs	Document the caregiver's relationship to the patient, their living situation, employment, and whether care is being provided for other dependents (eg, children)
	Assess the caregiver's capacity and willingness to provide care
	Inquire about the caregiver's physical and mental health
	Assess the impact of caregiving, including social isolation and financial strain
	Inquire about the caregiver's perception of the patient's status and ability for self-care
Refer to appropriate services and resources	Refer the caregiver to locally available resources:
	Palliative care teams, hospice,
	Home care services, respite care
	Social work, psychology, spiritual care
	Community resources, support groups, online resources
Educate about practical aspects of caregiving	Ensure the caregiver and patient have a joint understanding of the patient's cancer, its treatment, its typical course, and signs of advancing disease
	Check understanding of pain control (eg, dosing, adverse effects, addiction potential)
	Ensure education for practical skills (eg, dressing changes, injections, lifting/transferring)
	Highlight the importance of personal health and self-care and the availability of benefits and services for caregivers
Support caregivers through bereavement	Clarify when it is important to call and who should be called
	Be available by phone or in person to discuss caregiver concerns
	Offer referral to local bereavement support services
	Call or send a card to the caregiver after bereavement

It is important to determine whether the primary caregiver lives or will live with the patient, whether they have other dependents or work outside the home, and whether others will also provide assistance. Assessment of the caregiver's capacity and willingness to provide care is crucial; although it may be the patient's wish to stay at home and ultimately to die there, the caregiver may not be able to support this. The caregiver's physical and mental health, the impact of caregiving, and available social and financial resources should all be considered in assessing their well-being and their capacity to provide care. Last, caregivers can provide an important perspective on the functional and cognitive status of the patients they care for and their ability to provide self-care.<sup>77</sup>

### Refer to Appropriate Services and Resources

Physicians should be aware of and provide timely referral to resources that provide assistance and support for patients as well as caregivers. Complex caregiver-specific or dyadic interventions are often not readily available.<sup>34</sup> However, most cancer centers have palliative care teams, which offer team-based, family-centered support for patients and their caregivers. In addition to evidence from randomized controlled trials showing improved mental health and satisfaction with care,<sup>70-73</sup> qualitative accounts from caregivers describe the support for both patients and caregivers as a unique benefit of the palliative care consultation.<sup>82,83</sup> Expansion of palliative care services into outpatient settings and earlier referral to these services can provide much-needed support for caregivers.

Referral to other support services can be provided by the oncology team or facilitated by the palliative care team. These include home services, such as medical or non-medical home care; community services, such as support groups; services to promote safety and assist with daily needs, such as medical alert services or meal delivery; referral to professional counseling from social workers or psychologists; and admission for respite care to provide relief for the caregiver.<sup>77</sup> There are also numerous online resources available for caregivers, including through national cancer organizations as well as through the National Alliance for Caregiving and the Family Caregiver Alliance.<sup>84,85</sup>

### Educate About the Practical Aspects of Caregiving

Education about the cancer itself is as important for caregivers as for patients, including information about the stage of disease, the proposed treatment, possible adverse effects and their management, and realistic short- and long-term goals of care.<sup>86</sup> This information will have a direct impact not only on treatment decisions but also on decisions for the caregiver related to taking time off work, hiring professional help, advising family members living abroad to visit, or arranging transfer to an inpatient facility. Caregivers are involved in increasingly complex medical care, including managing medications, giving injections,

and wound care; this requires appropriate training, which can be provided by a nurse and/or pharmacist. Pain management and recognition of signs of decline in patient status are topics of particular relevance in advanced cancer settings.<sup>7,87</sup>

Caregivers are at risk for burn-out and should be encouraged to take time for themselves and to see their own physician regularly.<sup>34</sup> In addition, they should be informed of any personal benefits that may provide relief. For example, in Canada, the Compassionate Care Benefit provides up to 28 weeks of paid leave to caregivers providing care for a terminally ill patient.<sup>88</sup>

### Support the Caregiver Through Bereavement

Support for family caregivers includes all of the domains above, including acknowledging them as providing as well as needing care, assessing their needs, referring to appropriate resources, and providing education. Above all, caregivers want to be respected and heard. Complaints about end-of-life care by bereaved caregivers are often about the quality and quantity of communication.<sup>89</sup> Resources for bereavement support should be offered routinely, and physicians should be available to answer any outstanding questions that the caregiver may have. This is particularly important if risk factors for adverse bereavement outcomes have been identified, such as poor social support,<sup>44,45</sup> pre-loss depression,<sup>44-46</sup> or lack of preparation for the patient's death.<sup>44,45,49</sup> Bereavement support by the physician in the form of a telephone call or card is perceived by caregivers as supportive and enabling closure.<sup>90,91</sup>

Family caregivers constitute a large proportion of the health care work force for patients with advanced cancer but are at risk for a number of adverse outcomes, both while caring for the patient and after bereavement. Anxiety and depression are particularly prevalent and may be compounded by financial strain, poor social support, and the patient's advancing illness and declining status. There is an encouraging recent surge in trials assessing caregiver outcomes, but it is difficult to draw firm conclusions from these or to recommend a particular intervention. There is a need for additional trials that are specifically powered for caregiver outcomes, use measures that are validated for caregivers in advanced cancer settings, and assess interventions that are easily provided to this overburdened population. Early palliative care interventions are promising and have the advantage of using a resource that is already recommended as part of routine cancer care<sup>12</sup>; embedding caregiver-specific interventions into these trials should be further explored. The provision of online support for caregivers is also a practicable option that should be further tested in randomized trials. In the meantime, the CARES approach may offer a practical framework to provide palliative care for family caregivers while engaging them as active participants in patient care.



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#### **AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST**

##### **Palliative Care for Family Caregivers**

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