Palliative Care: Managing Caregiver Burden

What We Know

 › Palliative care (PC), or comfort care, is a specialized type of patient care that aims to promote comfort and maintain the highest quality of life of clients for as long as possible\(^{(29)}\)
   • By definition, PC can span an extended period of time, encompassing the active treatment phase of disease, disease remissions, recurrences of disease, and the decline in health before death. Although not limited to end-of-life care, PC usually is provided for patients with terminal illnesses\(^{(29)}\)
   > This approach to care involves an interdisciplinary palliative care team (PCT), which includes physicians, nurses, clergy, social workers, hospice staff, the client, and the client’s caregivers\(^{(10,27)}\)
     • Caregivers are the persons who are responsible for the client’s day-to-day care. PC is typically provided in the home setting by untrained caregivers, including spouses/partners, adult children, close friends, and relatives\(^{(1,8)}\)
       – These caregivers most often have no medical or nursing training, yet assist the client in meeting his or her physical and psychological needs
       - Data from the National Alliance for Caregiving and AARP study in 2015 indicated that\(^{(19)}\)
         - Over 43 million caregivers were providing unpaid care in the prior 12 months
         - Three in five care recipients have a long-term physical condition with high levels of need (e.g., dementia or at least two self-care needs)
         - Caregivers spend on average 24.4 hours a week providing care
         - Historically, women have been the primary nonprofessional caregivers; however, the number of nonprofessional male caregivers has risen to nearly 40% of all caregivers
       – The primary caregiver often lives with the ill person and receives some support from friends or members of the extended family\(^{(2)}\)
   > Several trends are contributing to an increase in the amount of time that palliative care is provided by caregivers. These trends include new and improved treatments for diseases, resulting in longer lives for patients; patients being discharged from hospitals more quickly; and more treatments being provided in ambulatory settings\(^{(24)}\)
     • Essential areas of PC, as recognized by caregivers, include\(^{(25)}\)
       – adequate pain management and symptom relief for the client
       – preserving client dignity
       – enabling the client to maintain a sense of control
       – helping the client prepare psychologically for death, when appropriate
       – strengthening relationships between the client and loved ones
   > The client’s illness and the intensity of his or her daily needs can have a negative impact on caregivers’ mental and physical health\(^{(2,17)}\). Caregivers are in the unique position of giving care and support, while requiring care and support from others themselves, to help manage caregiver burden\(^{(8,29,30)}\)
Caregiver training has been shown to be helpful (e.g., using medical equipment, providing mouth care, managing medication, tube feeding, colostomy care, treating bedsores): the more skilled the caregiver and the greater his or her level of self-efficacy, the more effective he or she is in providing care to the loved one (1,3,22,30).

As the client’s disease progresses, a caregiver must cope with taking on new roles in his or her relationship with the client, trying to stay positive for the client, and/or acquiring new skills in caring for the client (3,29).

Caregiver challenges include lack of personal time, financial burdens related to the client’s illness, isolation, and work schedule complications (1,30).

Caregiver burden may arise from feeling they did not have a choice in caring for their loved one, having to use complex medical technology in caring for the client, having little or no respite from care, constraints on time, difficulty balancing the caregiver role with other work or family roles, social isolation, financial problems, and trouble accessing services (16,19).

Fatigue, both in clients receiving palliative care and in their caregivers, can increase the perceived caregiver burden (23).

Researchers studying caregivers of cancer patients found that caregivers had fatigue scores that ranged from 23 to 26 on the Caregiver Strain Index, whereas scores of healthy control subjects averaged 19.9 (23).

The caregiver’s role often has a more negative impact on his or her mental health than it does on physical health.

- Depression and anxiety are commonly reported among caregivers, especially female caregivers (3,7,13,32).
- Depression and anxiety in the caregiver can lead to social isolation and lack of interest in previously pleasurable activities, as well as increased fear and restlessness (2).

- Anxiety may be exacerbated by lack of information about available support services and ways of accessing these services, as well as fear of a negative reaction from the healthcare team if such services are requested.
- Caregivers should be provided with information about individual counseling and/or support groups and should be encouraged to maintain social contacts to cope with stress (32).
- Where appropriate, they should be given referrals for adult daycare services, home nursing visits, and information about telephone services (e.g., support hotlines) to help relieve caregiver burden.

Caregivers report the need to feel confident in the work they do and in the care the client is receiving. Trust in the healthcare team and belief that the team is there when needed can bring relief to caregivers and increase their sense of control and confidence in the care they provide to their loved one, which can lead to increased caregiver security (6).

- Support from the PCT has been shown to decrease hospital admissions and facilitate the wishes of clients who want to die at home (22).

Caregivers see communication among the client, family, and PCT as the key to providing optimal PC for the client (10,21).

- Investigators have found that better communication is equated with higher caregiver satisfaction and better awareness of client wishes (10,21,25).
- Caregivers see improved communication as their greatest unmet need (6,8,21,25).
- Scheduled family meetings between family caregivers, the client, and the PCT allow the client to express his or her wishes regarding PC. These meetings can serve as a forum for caregivers to ask questions and stay informed of treatment goals and illness progression. Family meetings may be a good time to discuss symptom control and plan for the future (8,21).

Interventions with caregivers designed to increase their sense of preparedness and competence can result in an overall improvement in their psychological well-being (12).

Caregivers’ needs change as the client’s illness progresses. Multiple factors can cause caregivers to feel that their needs are not being met. Caregivers may put the client’s needs before their own, refrain from asking for what they need, feel that they should be able to do everything on their own, or have feelings of guilt that they are not doing enough for the client (1,9,22,30).

- Seeing the needs of the ill person as primary, caregivers often fail to recognize their own needs (22,29).
- As the client’s health declines, the PCT needs to anticipate the caregiver’s changing needs and offer support (6,22).

- Mindfulness training for caregivers has been shown to reduce depression and caregiver burden and increase caregiver quality of life. Simple, short, and low-cost, mindfulness-style interventions can be introduced at any time during PC (15).
- Identifying secondary caretakers to provide respite and emotional support to primary caretakers can help reduce caregiver burden, yet secondary caretakers often are an underutilized resource (5,32).

Caregiver training has been shown to be helpful (e.g., using medical equipment, providing mouth care, managing medication, tube feeding, colostomy care, treating bedsores): the more skilled the caregiver and the greater his or her level of self-efficacy, the more effective he or she is in providing care to the loved one (1,11,18,19,31).
What We Can Do

› Learn about the challenges of providing PC as seen by caregivers and clients; share this knowledge with your colleagues
› Develop an awareness of your own cultural values, beliefs, and biases, and develop knowledge about the histories, traditions, and values of your clients. Adopt treatment methodologies that reflect the cultural needs of the client(2,4,14,20)
› Internationally, social workers should practice with awareness of and adherence to the social work principles of respect for human rights and human dignity, social justice, and professional conduct as described in the International Federation of Social Workers (IFSW) Statement of Ethical Principles, as well as the national code of ethics that applies in the country in which they practice(14). For example, in the United States, social workers should adhere to the National Association of Social Workers (NASW) Code of Ethics core values of service, social justice, dignity and worth of the person, importance of human relationships, integrity, and competence; and become knowledgeable of the NASW ethical standards as they apply to palliative care and managing caregiver burden and practice accordingly(20).
› Learn and practice therapeutic communication skills with an emphasis on honesty, empathy, and patience.(26) Use language the client and caregiver can easily understand. Be sure they are receiving the same information from each member of the PCT(21)
› Be sure caregivers are familiar with members of the PCT and how to contact them. This will add to caregiver security and may allow the client to benefit from home care for a longer period of time
› Provide support to caregivers by recognizing their physical, emotional, and financial stresses and assessing their social supports(32) • As the client’s disease progresses, assess the need for referrals to social service agencies, physical or occupational therapy, home nursing care, and healthcare assistants • Encourage the caregiver to maintain or resume involvement in his or her own hobbies and activities, ask for help from others (e.g., friends, family), and take time for him- or herself, focusing on his or her physical, social, and spiritual well-being(13)
› Encourage the client and family to participate in activities they enjoy for as long as possible, to participate in religious or spiritual activities, and to avoid social isolation
› Encourage clients to prepare for end-of-life, while still living their life fully, through the use of an advance directive and assignment of a healthcare proxy. Encourage clients and families/caregivers to share their feelings about death
› Educate the caregiver regarding bereavement support and what to expect as the client’s health declines(1,31)
› Assist the caregiver in addressing feelings of grief and loss that arise with a loved one's decline and death. Be aware of where the caregiver is in the grief process and make referral to a mental health clinician if indicated (e.g., if client has symptoms of depression, anxiety, or post-traumatic stress disorder)(1,28)
› Provide written information, if available, to reinforce verbal education

Coding Matrix

References are rated using the following codes, listed in order of strength:

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<tr>
<th>Code</th>
<th>Description</th>
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<td>M</td>
<td>Published meta-analysis</td>
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<tr>
<td>SR</td>
<td>Published systematic or integrative literature review</td>
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<tr>
<td>RCT</td>
<td>Published research (randomized controlled trial)</td>
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<td>R</td>
<td>Published research (not randomized controlled trial)</td>
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<td>C</td>
<td>Case histories, case studies</td>
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References


