



National Hospice and Palliative Care Organization
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**FAMILY CAREGIVERS IN PALLIATIVE
CARE AND HOSPICE: MINIMIZING
BURDEN AND MAXIMIZING SUPPORT**

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INTRODUCTION

Family caregivers provide substantial care to patients with serious illness and are themselves in need of care. Family caregivers are involved in direct care, decision-making, goal-setting, and advance care planning. As professionals, we play a vital role integrating caregivers into the plan of care and supporting them in their roles. This resource will present a conceptual framework for working with caregivers across the trajectory of advanced illness, including strategies for assessment and intervention.

CONCEPTUAL FRAMEWORK

The following theoretical concepts provide a useful structure within which to frame the work with family caregivers.

The Stress Process Model looks at the intersection of fixed characteristics (age, gender, and relationship with the person who is ill) and the dynamic characteristics (living arrangements, relationship quality, family functioning, and developmental stage).

- In this model, caregiver stressors are considered dynamic because they ebb and flow over time.
- Within this model, caregiver burden occurs when demands exceed coping (Pearlin, 1981, 1990, 1997; Fletcher, 2012).

Attachment Theory was first defined by Bowlby in 1981.

- Within the context of caregiving, strong attachment is associated with a higher sense of commitment to provide care and a lower sense of subjective burden.
- However, a strong sense of obligation can also result in higher caregiver burden especially if caregivers are unable to balance caregiving with other activities (Bowlby, 1981).

Mutuality refers to reciprocity within healthy relationships and is usually associated with positive relationship quality between patient and caregiver.

- Better relationship quality is associated with a lower level of burden, depression, and resentment.
- Relationship satisfaction generally predicts better role adjustment for caregivers. This has been particularly well studied in spouses (Kim, 2008; Schumacher, 2008, 2010).

BEREAVEMENT

It is essential to understand bereavement and differentiate normal from complicated bereavement. As interdisciplinary team members work with the patient, they can interact with family caregivers and identify which caregivers exhibit risk factors for complicated bereavement.

Key definitions:

- Loss implies being deprived of someone or something important.
- Grief is a normal reaction to loss.
- Bereavement is a period of grief and mourning after the death of someone close.
- Mourning is the psychological process of integrating grief, and is usually culturally determined.
- Anticipatory Grief is the expectation of the death.

ASSESSMENT

A comprehensive caregiver assessment should be done at intake and caregivers' needs should be reassessed over time. Ideally, the caregiver domains that are measured include physical well-being, psychological well-being, spiritual well-being, social well-being and cultural well-being.

Physical Well-Being

- Caregivers differ in their ability and willingness to manage the physical tasks associated with serious and advanced medical illness. As professionals, it is essential that we involve family caregivers in care planning without making assumptions about them. These questions may be helpful:
 - ◆ What specific help do patients need with activities of daily living?
 - ◆ Can the caregiver provide the assistance the patient needs?
 - ◆ Is the caregiver able and willing to monitor symptoms on behalf of the patient?
 - ◆ Can the caregiver assist with management of prescription medications?
 - ◆ Does the patient live alone or with the caregiver?
 - ◆ Are the living arrangements conducive to safety and good quality of life?
- Generally speaking, caregivers who live with the patient and those who experience sleep disruption report higher burden.
- Caregiving can take a physical toll and cause joint and muscle pain, fatigue and immune system deficiencies.
- Active caregiving is often associated with lower self-care.
- Certain caregiving tasks, especially bathing and toileting, are associated with lower caregiver well-being.

Research Study

AARP conducted a survey of 1,677 family caregivers in the US. Results suggest that family caregivers are managing a broad array of medical and nursing tasks in the home setting. In this study, these tasks were defined as: medication management, helping with devices to improve mobility, preparing special food, wound care, and managing monitors, incontinence, and specialized medical equipment.

- 46% of caregivers performed medical and nursing tasks.
- 78% of caregivers managed medications, IV's, and injections.
- 35% of caregivers were doing wound care.
- 35% of caregivers functioned as care coordinators.
- 69% of caregivers reported no home visits by healthcare professionals.
- Over 50% of caregivers said they felt they had no choice, there was no one else to help, and insurance would not cover services.
- Caregivers reported both positive and negative effects.
- Most caregivers felt they were helping to avoid institutionalization (AARP, 2012).

Based on study findings, AARP developed a set of ten clinical, educational, policy and research recommendations to address the needs of family caregivers who have taken on the triple burden of personal care, household chores, and medical/nursing tasks.

Social Well-Being

- Living with the patient is associated with increased caregiver isolation.
- Some caregivers experience erosion of social support, especially if the illness is prolonged.
- Most caregivers report financial concerns.
- Employment is protective for caregivers, probably because of the inbuilt socialization and social support aspects.
- Social support networks can be protective against caregiver burden.
- Long distance caregiving is increasingly common across the US with the primary caregiver often in a different state, which presents a series of logistic and communication challenges.

Psychological Well-Being

- A comprehensive assessment should be done to evaluate caregivers for depression and anxiety.
- Caregivers' past coping can be used to assess their current strengths and resources.
- It is necessary to assess the family's developmental stage:
 - ◆ What losses are typically associated with this life stage?
 - ◆ What are the current needs, challenges and resources of the family unit? If the caregiver is elderly, the caregiver may have parallel health care needs and conditions.
 - ◆ If the caregiver has young children, he/she may feel torn between caregiving duties for the person who is ill and the children
 - ◆ How will the illness and treatment demands affect the family unit? (Raveis, 2005; Stroebe et al, 2006)

Spiritual Well-Being

- When working with caregivers at the end of life, it is essential to conduct a spiritual assessment.
- Members of the team should assess the caregivers' existential perspectives on hope and suffering.
- Professionals should recognize spiritual strengths such as faith and meaning.
- Professionals should recognize risk factors such as a crisis of faith, hopelessness, anger, and questions like: Why me?
- It is important to recognize when referral to a chaplain is needed.

Cultural Well-Being

- Cultural norms of families must be respected.
- Cultural differences between professionals and patients can lead to underestimation of caregiver distress.
- The cultural imperative through which caregivers are expected to provide care may pose a barrier to accessing formal services; this is typical among immigrant families.
- Some cultures have inbuilt taboos against verbalizing death. These can obscure care planning, but should be respected.
- Professional interpreters should always be used instead of family (Aliyu, Adediran, & Obisesan, 2003; Weiner, Arnold et al, 2006; Glajchen, Homel et al, 2013).
- Caregiving can be rewarding for caregivers, although this area is less well developed in research.
- Potential rewards of caregiving include:
 - ◆ Discovery of personal strength through adversity
 - ◆ Improved sense of self-worth

- ◆ Deepening of the relationship with the patient
- ◆ Sense of personal growth
- ◆ Sense of fulfilling an obligation (Balducci, 2008)

Research Study

A least one study suggests that caregivers who feel more prepared also derive more benefit from their role as caregivers. Family caregivers (n = 125) of patients receiving specialized palliative care were recruited from four settings and asked to complete a questionnaire that included the Rewards of Caregiving Scale (RCS). Results demonstrated that more prepared caregivers with higher levels of hope felt less anxious and more rewarded by caregiving. So although the caregiver role is complex, this suggests that preparedness, anxiety, and hope can and should be targeted. (Henriksson A , Carlander I, Årestedt K, 2015).

CARE TRANSITIONS

The care transitions literature provides a framework for understanding the path taken by people with advanced and terminal illness. It may be useful to apply this framework to working with caregivers as well.

Diagnosis: During the phase of initial diagnosis, the caregivers have to integrate new medical information and unfamiliar terminology.

Treatment: During the treatment phase, caregivers may be asked to help the patient make decisions, while also juggling competing demands and providing support.

Recurrence: If the patient experiences recurrence of their disease, the caregiver may have to participate in a new round of treatment, and help the patient manage symptoms while also preserving hope.

Home care: During home care, the caregiver usually has to manage the patient's symptoms at home, which may include making adjustments to the environment.

Placement: If the patient decides to enter an institution, both the patient and caregiver will have to adjust to the new environment and change in role status.

Disease progression: Within the context of disease progression, the caregiver has to adapt to new functional limitations, which may expand the caregiver role.

Palliative Care and Hospice: As the disease progresses, the caregiver has to discuss or agree to new goals of care, a supportive care focus and a new team.

Survivorship/Cure: For patients who achieve remission or cure, caregivers have to resume normal life, albeit with uncertainty.

Death: As patient's progress to the terminal phase, caregivers bear witness to the suffering of their loved one, and have to achieve closure.

DOMAINS OF PALLIATIVE CARE

Clinical practice guidelines for quality palliative care were published by the National Consensus Project for Quality Palliative Care and led to a framework for treatment called the eight domains of palliative care. This approach can inform our work with family caregivers.

Domain One: Structure and Processes of Care

- Without making assumptions, it is important to ask the patient to identify the primary caregiver(s).
- If possible, it is advisable to meet separately with the primary caregiver to assess his or her needs.
- Caregivers should be involved in decision-making and care planning from the start.
- As professionals, we should:
 - ◆ validate the role of the caregiver
 - ◆ educate caregivers about the diagnosis and prognosis of the patient
 - ◆ review the range of treatment options with benefits and burdens
 - ◆ ensure caregivers understand different settings of care

Domain Two: Physical Aspects of Care

- As part of care planning, caregivers' fatigue, sleep disruption and functional limitations should be evaluated.
- It is essential to assess caregivers' willingness and ability to help with ADL's, IADL's.
- An environmental assessment of the home setting should be done before the care plan is finalized.
- Certain factors can improve coping in caregivers:
 - ◆ home care services
 - ◆ skills training which increases caregiver preparedness
 - ◆ self-care

Domain Three: Psychological and Psychiatric Aspects of Care

- As a direct consequence of assuming the caregiver role, caregivers in the palliative, hospice, and bereavement phases are at increased risk for psychiatric morbidity.
- At times, the psychological burden of the caregiver can exceed that of the patient.
- Distressed caregivers can influence patient well-being.
- Interventions are needed to directly support caregivers:
 - ◆ mild anxiety and depression respond well to counseling
 - ◆ interventions can help caregivers manage psychological reactions
 - ◆ resilience and past coping skills should be reinforced
 - ◆ consider referral for more persistent, longstanding, or complex psychiatric comorbidity
 - ◆ start the work of anticipatory bereavement (Williams AL, McCorkle R. 2011).



Research Study

- Caregivers differ in their responses to the loss of a loved one.
- Over 50% of bereaved caregivers report clinically significant depressive symptoms 1 year after the death of their relative.
- Being bereaved predicts poorer mental health and greater psychological distress 8 years after the death.
- Models of attachment maintained by relationships in adulthood play a role in determining the nature and severity of grief reactions following loss of a spouse.
- Predictors and Risk Factors:
 - ◆ Better quality of patient death reduces risk of bereavement regret.
 - ◆ Incidence of major depressive disorder is more likely for caregivers with mental health difficulties before the loss of the patient.
 - ◆ Completion of a DNR order is predictive of improved mental health from before the death of the patient to after the death (Kim et al, 2016).

Domain Four: Social Aspects of Care

- Patients and caregivers benefit from entitlements, including financial assistance, and community resources, as these provide support and offset caregiver burden.
- Isolated caregivers should be identified as they are likely to need more help from the formal system.
- Skill training improves competence and confidence.

Domain Five: Spiritual, Religious, Existential

- Spiritual care should be made available to caregivers.
- One of the members of the team should conduct a spiritual assessment:
 - ◆ address suffering, regret, legacy, closure
 - ◆ discuss spiritual and religious concerns
 - ◆ respect issues that the patient and caregiver do not wish to discuss

Research Study

- A recent hospice study identified the importance of addressing relational conflicts if these are important.
- Caregiver priorities included: regret, shame, desire to repair the relationship, and forgiveness.
- The study shows that available opportunities for life closure, growth, emotional healing, and reconciliation exist even in the setting of end of life. (Exline JJ, Prince-Paul M, Root BL, et al, 2012)

Domain Six: Cultural Aspects of Care

- It is essential to respect language.
- Information should be tailored to the patients' and caregivers' level.
- It is important to understand the caregivers' cultural beliefs and preferences for truth-telling, decision-making, and burial.
- The caregivers' cultural values should be communicated to the team.
- The use of professional interpreters is preferable to using family members.

Domain Seven: Care of the Patient at the End of Life

- When working with caregivers at the end of life, it is helpful to intensify caregiver support.
- It is useful to communicate the signs and symptoms of death so caregivers know what to expect.
- At the same time, it is essential to be vigilant in language and help demystify emotionally charged terminology including:
 - ◆ comfort care
 - ◆ patient is DNR
 - ◆ persistent vegetative state
 - ◆ there is nothing more we can do
 - ◆ Do you want us to stop everything?

Research Study

- Poor psychosocial health outcomes exist beyond the first year of bereavement.
- Over 52% of caregivers in one study had one or more suspected psychiatric disorders, mostly anxiety.
- Comprehensive evaluation of psychiatric morbidity is often missing in clinical practice due to time resources (Rumpold T, Schur S, Amering M, et al, 2015; Masterson MP, Hurley KE, Zaider T, et al, 2015).

Domain Eight: Ethical and Legal Aspects

- As part of goals of care discussions, it is important to help patients identify a surrogate.
- Ensure the surrogate agrees to assume the role.
- Ensure the surrogate understands the patient's wishes.
- Document goals of care and treatment preferences.
- Help patient complete advance directives, living will vs oral.
- Convert treatment goals into medical orders.

THE FAMILY MEETING

- No single definition exists in the literature
- The Family meeting can be called by patient, family or staff and is a valuable clinical tool for:
 - ◆ communicating medical information
 - ◆ delineating goals of care
 - ◆ facilitating decision-making
 - ◆ paying attention to patient preferences
 - ◆ processing emotions in a safe setting
 - ◆ acknowledging the central role of the caregiver

The Family Meeting: Triggers

- Family conflict or crisis
- Longer length of stay
- Absence of designated health care agent
- Major care decisions

- Discharge planning
- To share unwelcome prognostic information (Billings, 2011)
- Change in medical status
- Transition points in care
- Advance care planning
- Patient/surrogate decision-making
- Conflict resolution
- Ethical dilemmas (Back A, Arnold R, Tulsy J, 2009; Hudson P, Quinn K, O'Hanlon B, Aranda S et al, 2008)

The Family Meeting: Benefits for Caregivers

- It is a helpful place to validate the central role of caregivers
- Creates a safe environment for goals of care discussions
- Forum to check caregivers' understanding
- Place to process intense emotions and provide support
- Lends itself to interdisciplinary care
- Can be a forum to share decision-making, reach consensus
- Optimal number: less is better; number of staff should not overwhelm family
- Optimal time: 1 hour prep time, 1 hour meeting, 30-60 minutes follow-up
- Optimal choice of participants:
 - ◆ Patient
 - ◆ Caregiver/s invited by the patient
 - ◆ Involved health care professionals

Research Study – What We Know About Family Meetings

- What benefits the patient benefits the caregiver.
- Earlier referral to palliative care and hospice reduces patient's symptoms and also benefits caregivers.
- Earlier hospice referral and longer enrollment are associated with less caregiver depression.
- Lower rates of ventilation, resuscitation, less ICU time are associated with higher satisfaction and less PTSD.
- The literature on the family meeting is still relatively new.
- Existing studies suggest that benefits outweigh risks.
- Canadian study confirms the value of planned multidisciplinary family meetings in specialist inpatient palliative care units.
- Family caregivers reported a statistically significant increase in having their care needs met, in a before-after Australian study using a trained palliative care nurse; they also reported that the meetings were useful. (Hannon, O'Reilly, et al, 2012; Hudson, Thomas, 2009)

CONCLUSIONS:

Research Study: Experience at End of Life

Joan Teno's group has evaluated the US dying experience. In a survey of family members/other informants of 1578 decedents, the study team asked informants about the patient's experience at the last place of care at which the patient spent more than 48 hours. The main outcome measures were patient- and family-centered:

Did health care workers...?

- provide desired physical comfort and emotional support to the dying person,
- support shared decision-making,
- treat the dying person with respect,
- attend to the emotional needs of the family, and
- provide coordinated care (Teno J, 2004)

Caregivers reported the following concerns:

- inadequate treatment for pain, dyspnea (25%)
- concerns with physician communication (25%)
- insufficient emotional support (35% from home health, LTC, or hospital)
- Caregivers of patients receiving hospice were more satisfied with quality of care, with 70.7% rating care as "excellent" compared with less than 50% of those dying in institutions or with home health. Therefore, family members of decedents who received care at home with hospice services are more likely to report a favorable dying experience.

Conclusion

To ensure that caregivers' needs are met, high standards are needed in knowledge, clinical competency, and understanding of best practices. Working with caregivers falls to no one member of the health care team, but rather, falls to every member. Specific caregiver interventions, such as the family meeting, should be quality indicators in palliative care and hospice.

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