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The assessment and management of family distress during palliative care

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Abstract

Purpose of review—In the advanced stages of illness, families manage multiple caregiving demands while facing the emotional task of preparing for the loss of their loved one. Palliative care settings are well suited to identifying families at risk for elevated distress, and providing support as they navigate this process. This review summarizes current research in the assessment and management of family distress at the end of life.

Recent findings—The recent literature on families of terminally ill cancer patients has provided a more precise description of the relational and cultural factors that contribute to family distress. Studies eliciting the perspectives of family members on what is needed at the end of life affirm the importance of supportive communication and continuity of psychosocial care into bereavement. Other developments include efforts to establish guidelines for conducting family meetings in the palliative care setting, and to train palliative care practitioners in family-centered assessment techniques. Finally, there is a limited but growing evidence base for the utility of delivering family-focused psychosocial interventions during palliative care.

Summary—The knowledge gained from current research on what is most salient to family members during palliative care is critical for ensuring effective delivery of supportive services and collaborative engagement in those services.

Keywords

cancer; distress; family; palliative; psychosocial

Introduction

In the advanced stages of cancer, the families of dying patients manage multiple caregiving demands, serve as liaisons to healthcare providers and participate in critical decision-making processes. Simultaneously, families face the emotional task of preparing for the loss of a loved one. Although many family members show remarkable resilience during this time, studies consistently identify a high-risk group of 18–35% who suffer significant psychological morbidity [1–4]. When compared with families in the curative phases of cancer treatment, families in palliative care show substantially worse quality of life, with

greater disruptions to their own health and daily activities [5,6]. Accordingly, a consensus statement issued by the National Institute of Health on End of Life Care emphasized the importance of addressing the needs of family caregivers as they prepare for the death of a loved one [7]. The present article presents current perspectives on family distress at the end of life. We begin with an overview of recently published work on the nature and assessment of family distress, followed by a review of supportive interventions for families at the end of life.

The assessment of family distress

The distress that reverberates throughout cancer families has been described extensively [8]. Recent literature features a number of developments that inform the assessment and management of family distress at the end of life, including a more precise description of the relational and cultural factors that contribute to family distress; the articulation of family members' perspectives on what is needed to optimize quality of life during palliative care; and practice guidelines for the assessment of families during palliative care.

Understanding family distress at the end of life

The detection of family distress during palliative care involves an appraisal of both individual and relational functioning, two distinct but closely related processes. A clear understanding of what constitutes these areas of functioning is needed to better target the assessment of families. Recent studies have taken a closer look at relational functioning as a salient dimension of family members' quality of life. Relational concerns are shared by patients and families alike at this stage of illness. Prince-Paul elicited perspectives from terminally ill cancer patients about the importance of close relationships as they approach dying [9^{**}]. Patients affirmed the sense of purpose derived from their relationships, expressed a desire to share gratitude and love with close family and friends, resolve disputes and heal fractured relationships. Whereas social functioning is commonly evaluated as a global dimension of quality of life, certain relational experiences may be especially valued by dying patients.

A study by Persson *et al.* [10^{*}] also highlighted the emergence of relational concerns at the end of life. They examined health-related quality of life among the significant others of dying lung cancer patients. Soon after diagnosis, the average level of family functioning (i.e., satisfaction with cohesiveness, support, and communication) was comparable to the general population. However, as illness progressed, ratings of family functioning worsened significantly, so that by the patient's death and 6 months afterward, significant others scored below the general population in these domains. The capacity to sustain adaptive family functioning may become more challenging as the disease progresses, making the assessment of families particularly important during palliative care.

Prior research has tended to emphasize the explanatory role of relational functioning as a determinant of individuals' levels of distress and psychological adjustment [11]. An alternative perspective is to construe relational difficulties as part of the phenomenology or even the consequence of individual distress. In a Finnish study of 85 cancer families with

young children, Schmitt *et al.* [12^{*}] found that maternal depression, regardless of whether the mother was the cancer patient, was a strong predictor of poor family functioning, particularly in domains of problem solving and role functioning. Another strong predictor of family functioning was sense of coherence (SOC), a construct referring to individual family members' capacity to make sense of the illness, and develop a coherent and meaningful narrative about its implications. The capacity to make meaning of the cancer experience, though assessed at the individual level, is presumed to be a potential source of resilience within the family. The authors suggest that the assessment of these individual-level attributes (e.g., SOC, parental depression) in families with young children may inform clinicians of potential strengths and vulnerabilities that exist within the family as a whole.

Family members' adjustment when faced with the loss of a loved one is undoubtedly shaped by the broader institutional and cultural systems in which the family is embedded. The relevance of cultural context in understanding family distress at the end of life was highlighted in a study examining determinants of distress among Taiwanese family caregivers of terminally ill cancer patients [13^{**}]. The prevalence of clinically elevated depressive symptoms in a sample of 170 Taiwanese family caregivers of advanced cancer patients was particularly high (76%). A prevailing assumption had been that Taiwanese and Chinese caregivers were buffered against distress due to cultural norms that encourage caregiving and extol the virtues of filial obligation. The authors suggest instead that family caregivers who are motivated more by cultural expectations than by emotional attachment to the patient may in fact be more susceptible to distress. Further factors that distinguished distressed from nondistressed caregivers included being a spouse caregiver, having little confidence in knowing how to care for the patient at home, and perceiving the caregiving role as disruptive to one's own health.

Interestingly, Taiwanese caregivers who felt that they knew the patient's thoughts and feelings about the disease were less likely to endorse symptoms of depression. Furthermore, the more contact and communication caregivers had with the patient, the more likely they were to feel they understood the patient's subjective experience. The tendency toward nondisclosure and limited communication that is characteristic of East Asian cultures may have a constraining influence on relationship growth. This suggests that attitudes toward, and adherence to cultural norms among Taiwanese caregivers needs to be considered in assessing their psychological adjustment during the advanced stages of disease.

Identifying family needs at the end of life

Research on end of life care has consistently highlighted the importance of effective communication during the terminal stage of illness [14–16]. Hebert *et al.* [17^{**}] conducted focus groups with both active and bereaved family caregivers to elicit their perspectives on what questions they felt were most important to discuss at the end of life. Caregivers were mostly adult children of dying patients and had been recruited from palliative care and hospice services. The questions caregivers identified as important to discuss were classified into four broad domains: medical, practical, psychosocial, and religious or spiritual. In the psychosocial realm, relational concerns were prominent. Family members identified a need to receive support in managing communication and conflict within the family, as well as

knowing how to help young children understand the illness. Recent data presented by Wright *et al.* [18*] provided additional support for the notion that end-of-life discussions may yield downstream benefits for family caregivers. According to their survey of terminally ill cancer patients and their caregivers, patients who reported having end of life discussions with their physicians had fewer aggressive interventions at the end of life. Less aggressive care was in turn associated with better outcomes for bereaved caregivers, including lower risk for psychiatric morbidity, increased sense of preparedness, better quality of life and less regret.

Palliative care units are well poised to address the needs of family members both prior to the patient's death, and during bereavement [19]. Indeed, a model of continuity of care for families has been strongly endorsed [3]. Milberg *et al.* [20*] asked recently bereaved family members what kind of follow-up support they felt was needed after the patient's death. Nearly half (46%) perceived a need for bereavement follow-up support, particularly within the first 6 weeks of bereavement, and preferably in the home. Family members expressed a need to speak with someone who can facilitate the expression of grief, including feelings of guilt, regret and loneliness, and who knew the patient and family prior to death. The observation that a significant portion of family members perceived no need for follow-up support argues for the selective allocation of family support services. In order to identify those who may benefit from continued psychosocial care, a comprehensive assessment of family functioning is needed early in palliative care.

Guidelines for the assessment of families at the end of life

There has been limited empirical work focused on delineating and testing effective methods of assessing families in the palliative care setting. The use of screening questionnaires to detect individual-level distress among family members has gained recent empirical support. Zwahlen *et al.* [21] established the psychometric validity of the distress thermometer, an efficient way of identifying symptoms of depression and anxiety among family members of patients at various stages of disease. The Psychosocial Assessment Tool was also recently validated as a brief screening measure for the assessment of psychosocial distress in families of children newly diagnosed with cancer [22]. The aforementioned studies focused predominantly on the early and active treatment stages. Moreover, the screening methods evaluated in recent studies target the evaluation of individual-level functioning. In their prior work, Kissane *et al.* [3] advocated for the use of a screening tool called the Family Relationships Index [23] to assess aspects of family-level functioning (e.g., communication, conflict, cohesiveness) that may have been disrupted by illness.

Family conferences, held routinely on most palliative care units, present a valuable opportunity to assess levels of individual and relational distress within the family. On the basis of their review of the literature on family meetings in palliative care, Hudson *et al.* [24**] concluded that there is little empirical evidence on which to base the format and content of family meetings. Guided by the perspectives of an expert panel and their review of the literature, they created a set of practice guidelines for conducting family meetings in palliative care. Family meetings were conceptualized as a forum in which to clarify the goals of patient care, elicit concerns, and share medical information. The authors provided a

detailed description of the steps involved in setting up and conducting a family meeting. Although there is ample opportunity within this process for family members to identify their own needs for psychosocial care, their approach does not explicitly include an assessment of family functioning, or adjustment and coping among individual family members. Two additional issues raised by Hudson and colleagues deserve further consideration. One is the need for training among palliative healthcare professionals. A recent study found that delivering a communication skills training module to healthcare professionals on techniques of conducting family meetings in palliative care yielded increased self-efficacy and high satisfaction among those participating in the training [25]. A second issue concerns the coordination of roles within a multi-disciplinary team. Given the range of medical, psychosocial and ethical concerns that arise in the context of a family meeting, an integrative model that enables the co-facilitation of meetings by clinicians of different disciplines could help optimize the benefits gained by meeting with families.

Zaider and Kissane [26] recently presented a resilience-based approach to assessing areas of competence and distress among families in palliative care. This assessment model is based on empirical work conducted by Kissane and his research group over the last decade on family adaptation in palliative care [3,27]. A family meeting begins with a clarification of the family's understanding of the patient's illness, the goals of medical care, and future needs. This model departs from standard practice in that the meeting is then used to elicit perspectives on how family members themselves are functioning (e.g., how are family members managing emotionally? Is there concern for any particular family members?). Family strengths and resources are affirmed (e.g., level of commitment and caring for one another) and areas of relational distress are noted (e.g., poor communication, difficulty managing conflict or working together as a team). The assessment itself is a form of intervention, as family members become aware of their inherent competencies, patterns of relating, and changes in family life resulting from the illness. The meetings also enable clinicians to gauge the family's need for more extensive support.

Management of family distress in palliative care

Previous research has demonstrated the utility of delivering couples and family therapy at the end of life [28,29]. Family Focused Grief Therapy [27] is an example of an evidence-based intervention model that has been shown to reduce distress among palliative care families who are at high risk for longer term morbidity and complicated grief [28]. Using a group format, Hudson *et al.* [30**] recently found positive effects for a psychoeducational program for family caregivers transitioning to home-based palliative care. Across three sessions, trained healthcare professionals provided family members with information about their role within the palliative care team, a review of what services are available to them, strategies to use in response to the patient's needs, ways to manage their own needs, and information about what to expect when death is approaching. Caregivers who participated in this program reported improved preparedness for the caring role, increased sense of competence and caregiving reward.

Kirchhoff and Faas [31] summarized the recent literature on what supportive measures are needed by families at the end of life, drawing predominantly from research conducted in an

intensive care unit. The authors identify five domains in which psychosocial support is needed for families: decision-making; communication within the family and between family members and healthcare providers; upholding spiritual and cultural beliefs; preparing for death; and receiving continuity of care. The authors provide a comprehensive overview of the experiences of family caregivers as they navigate these aspects of palliative care. For example, they call attention to the broader emotional and social factors that can impede decision-making regarding advanced care planning or withdrawal of life support. Other challenges noted include the burden family caregivers feel when called upon to make difficult decisions; the feelings of guilt and regret following the decision; the potential for disagreements within the family about whether the best decision was made; and the limited coaching or support obtained from healthcare professionals, who may initiate discussions of death and dying without taking into account the family's readiness to do so. The authors review practical and cultural needs, such as needing to find comfort and meaning in prayer and religious practices, and the use of family visitations to accomplish important end of life tasks. They present a set of recommendations for the support of family members in the areas delineated earlier.

Conclusion

Although the need for family support during palliative care is fairly well established, there is a limited evidence base to inform clinicians about how to best intervene. Promising developments in the recent literature include efforts to establish guidelines for conducting family meetings and to train palliative care practitioners in family-centered assessment techniques. In addition, efforts have been made to bring the voices and subjective experiences of family members into the ongoing discourse on what is needed most at the end of life. Knowing what is most salient and meaningful to family members during palliative care is critical for ensuring effective delivery of supportive services and collaborative engagement in those services.

References and recommended reading

Papers of particular interest, published within the annual period of review, have been highlighted as:

- of special interest
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Additional references related to this topic can also be found in the Current World Literature section in this issue (pp. 87–88).

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focus groups with active and bereaved caregivers of terminally ill cancer patients in order to elicit their perspectives on what topic areas are most important to discuss at the end of life. Family caregivers identified topic areas that are not adequately addressed in end of life discussions with healthcare practitioners, including information about the dying process, how to manage family disagreements, the meaning of illness, and practical concerns (e.g., funeral arrangements). Barriers to asking questions were also explored. The findings from this study have clear implications for what needs to be included in end of life discussions. [PubMed: 18363491]

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