

Family Support in Palliative and Hospice Care: A Comprehensive Review

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Abstract

This review delves into the clinical significance of psychological and existential challenges faced by families caring for patients with life-limiting conditions throughout the course of the illness. The study underscores the importance of not overlooking these aspects in the context of palliative and hospice care. Existing literature reveals intricate constructions of various issues, desires, and influencing variables, highlighting the need for a more comprehensive understanding of the relatives' condition. The conclusion emphasizes the necessity for systematic and longitudinal research to delve deeper into the multifaceted experiences of families. Additionally, the development and testing of supportive interventions in randomized trials are proposed to enhance supportive care for families within palliative care and hospice practices.

Keywords: Palliative care; Hospice care; Family support; Psychological challenges; Life-limiting illnesses

Introduction

While palliative and hospice care aim to improve the quality of life for patients' families, there is limited understanding of their unique challenges and needs. To address this gap, we conducted a thorough literature review. From January 2017 to November 2018, we published a narrative review providing an expert overview of peer-reviewed, English-language original research publications and reviews on psychosocial and existential issues, supportive needs, and interventions for relatives throughout the patients' disease trajectory. A total of 64 publications were included in this comprehensive analysis. Throughout the entire illness trajectory, relatives consistently report significant levels of psychological and existential distress, burden, and morbidity. Additionally, families express an unacceptably high number of unmet needs, with information being the most pressing requirement. The challenges and desires of relatives are embedded in complex systems influenced by various socio-demographic variables, patient-relative relationships, and the interplay of numerous psychological processes. Research indicates that early support interventions for families along the illness trajectory are practical, and secondary data from randomized studies suggest that providing early palliative care to relatives has positive effects. There is a pressing need to incorporate a greater focus on addressing the needs of relatives in the daily practice of palliative and hospice care. Consequently, further research is essential to uncover more comprehensive and systematic information that can alleviate the psychological burden on relatives and enhance their overall quality of life. Family members often play a crucial role in providing assistance and care for individuals with life-limiting illnesses, serving as essential sources of information for the patients. Their influence extends beyond the patient's well-being and care situation, impacting the overall quality of life. Simultaneously, these relatives bear their own unique burdens and have specific needs related to the patient's illness [1,2].

Throughout the trajectory of the patient's condition, spanning from diagnosis to death and into the grieving process, various emotional, physical, and economic factors contribute to the families' burden. Interestingly, the psychological load on families can sometimes surpass the suffering experienced by the patients as they approach the end of life [3]. Palliative care aims not only to enhance the quality of life for the patient but also for their relatives and friends. Despite this, there is a notable imbalance in knowledge, with less understanding of the family's needs and concerns compared to those of the patients. An increasing number of studies have begun to shed light on the challenges

and demands faced by relatives and family caregivers during palliative and hospice care, as well as in the aftermath of bereavement [4]. Additionally, preliminary research has explored supportive strategies for families at various stages of the disease. The objective of this book is to provide an up-to-date review of the literature. A comprehensive examination of recent global studies has been undertaken to better comprehend the issues and requirements of relatives during palliative and hospice care for patients with life-limiting illnesses.

Materials and Methods

This narrative review encompasses all pertinent peer-reviewed publications from the past two years addressing psychological morbidity and burden, quality of life, existential distress, preparedness/self-efficacy, supportive needs, supportive interventions, and the role of specialist palliative and hospice care in patients facing advanced incurable diseases throughout the disease trajectory. To maintain focus, studies concentrating on relatives' issues and requirements during grieving were excluded due to the broad spectrum of topics covered. For the purposes of this research review, the term "relatives" encompasses friends, family, and informal carers of patients. The review encompasses all types of incurable and/or severe illnesses, as well as various palliative or hospice care arrangements.

Relatives psychological morbidity and burden

Enduring Psychosocial Distress has been documented at high levels in the literature, with three additional studies affirming these findings, revealing significant psychosocial distress in 66-96% of family caregivers across various palliative care settings. Ullrich's pilot study utilized a modified problem list from the Distress Thermometer [5], identifying melancholy, grief, and weariness as the most prevalent distress-causing situations (80-83 percent). Elevated distress levels appear correlated with a higher number of unmet requirements and dissatisfaction

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with patient treatment, aligning with previously reported concerns. Symptoms of Anxiety and Depression: Moderate to severe anxiety and depression were present in 43% and 41% of family caregivers of advanced cancer patients, respectively, upon admission to a palliative care ward. This aligns with two larger recent studies; Dionne-Odom et al. reported rates of 23% for high depression and 34% for borderline or high anxiety in 294 family caregivers of advanced cancer patients [6], while Goetze et al. reported high anxiety levels of 32% in 294 family caregivers [7]. Areia et al. found a high risk of anxiety in 72% and a high risk of depression in 69% of 112 family caregivers of patients with terminal cancer, with 51% reporting significant levels of somatization. Jennifer Temel's group investigated psychological morbidity in patients and family caregiver dyads in early palliative care for patients with newly diagnosed advanced lung or noncolorectal gastrointestinal cancer in a randomized controlled research. Patients reported higher depression symptoms, whereas caregivers reported more anxious symptoms, with anxiety and depression symptoms in dyads positively correlated [8]. Family caregivers' psychological morbidity was associated with younger age, female gender, relationship to the patient, caregiving role, satisfaction with health care professionals, shorter nighttime sleep, less physical activity, family functioning, and low engagement in self-care practices. In a study of 173 carers of advanced lung cancer patients, death fear was linked to dysfunctional attitudes.

Overall psychological burden: The comprehensive psychological burden experienced by families is influenced by a combination of anxiety, sadness, patient age, gender, and shifts in meaning. Williams et al. identified in qualitative research that stress among female family caregivers may stem from adherence to stereotypical gender norms that position women as primary caregivers [9]. In patients newly diagnosed with lung cancer, family caregivers' self-efficacy emerged as the most significant indicator of their psychological burden throughout the entire illness trajectory. Among 50 informal carers of patients with advanced cancer, perceived competence, resilience, and positive aspects of caregiving were the most robust predictors of burden.

Importance of care setting and utilization of support services: The psychological burden seems to be linked to the management of patients' psychological or psychiatric symptoms in family caregivers providing palliative or hospice home care. This connection is mediated by caregivers' use of escape-avoidance coping responses, their own health status, and their relationship to the patient, particularly if they are the spouse. According to Kobayakawa et al., 11% of caregivers have sought assistance from psychiatrists or psychologists to cope with patients' symptoms, while another 11% expressed the desire or intention to do so [10-15]. A significant study involving 373 cancer patient caregivers found that assisting with medical care was associated with increased emotional and psychological strain, while assisting with non-medical matters increased psychological burden and strained the caregiver-patient relationship. Direct involvement in patient care activities increased burden but improved connections with patients, indicating that the use of support services had mixed effects on burden.

Discussion

This narrative review, comprising 64 recent publications focused on the patient's disease trajectory, underscores the significant volume of new research addressing psychosocial and existential challenges, supportive needs, and potential interventions for relatives of patients with life-limiting diseases. Among the reviewed publications, 62 were original research studies (with 73 percent specifically related to cancer) and two were reviews from the past 24 months. The substantial increase

in publications on this subject reflects a growing recognition of the importance of incorporating patients' families into the perspectives and activities of palliative and hospice care. The research presented here explores various facets of relatives' issues and demands, revealing a broad spectrum of factors influencing relatives. However, forming a comprehensive understanding of the relatives' position is complicated by the diverse and heterogeneous nature of contributing factors. The studies not only covered a wide array of topics but also examined different target groups (relatives, family caregivers, families and friends, informal caregivers, family carers, carers, etc.) across various care settings, life-limiting diseases, stages, and cultural backgrounds. The challenge lies in the variability of putative risk variables investigated in these studies, making direct comparisons challenging. Many of the studies are cross-sectional, and the limited longitudinal studies cover different time periods. Additionally, terminology varies across studies, with phrases like "burden" and "psychological morbidity" interpreted differently. Notions such as "quality of life" were assessed and interpreted in diverse ways. Lastly, for quantitative evaluations, a range of measures and instruments were employed, and some questionnaires lacked validation for specific purposes. The need for standardized terminology, consistent measures, and validated instruments emerges as a crucial consideration for future research in this evolving field.

Conclusion

In summary, the psychological and existential challenges, along with the support needs of families caring for patients with life-limiting conditions, have demonstrated clinical significance throughout the entire duration of the patient's illness. It is imperative not to overlook these aspects in the context of palliative and hospice care. While existing studies have uncovered complex structures of various issues, desires, and influencing variables, there remains an incomplete understanding of the overall condition of the relatives. Moving forward, there is a pressing need for more systematic and longitudinal research to gain a deeper insight into the multifaceted experiences of families. Concurrently, the development and testing of supportive interventions in randomized trials are essential to enhance the provision of supportive care for families within the realms of palliative care and hospice practices. By addressing these research gaps and advancing evidence-based interventions, we can strive to improve the well-being and quality of life for families navigating the challenges of caring for loved ones with life-limiting illnesses.

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Conflict of Interest

Author declares no conflict of interest.

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