

Advances in Palliative and Hospice Care to Enhance the Quality of Life of Patients Family

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Abstract

Although palliative and hospice care strives to enhance the quality of life of patients' family, little is known about their unique difficulties and requirements. We provide a complete review of the literature. Between January 2017 and November 2018, a narrative review was published to provide an expert overview of peer-reviewed, English-written original research publications and reviews on psychosocial and existential problems, supportive needs, and interventions for relatives during the patients' disease trajectory. There were a total of 64 publications listed. During the patient's whole illness trajectory, relatives report significant rates of psychological and existential discomfort, burden, and psychological morbidity. Furthermore, family report an unacceptably high number of unfulfilled demands, the most pressing of which is information. Problems and wants of relatives are part of complex systems that are impacted. Problems and demands of relatives are part of complex systems impacted by a variety of socio-demographic variables, patient-relative relationships, and the interdependence of numerous psychological processes. Early support treatments for family along the illness trajectory have been shown to be practical, and secondary data from randomised studies suggests that offering early palliative care to relatives has positive impacts. Relatives should be addressed to a greater extent in the everyday practice of palliative and hospice care, therefore additional study is needed to uncover more comprehensive systematic information to reduce relatives' psychological load and enhance their quality of life.

Keywords: Palliative Care, Relatives, Family Caregiver, Needs, Quality of Life, Hospice Care

Introduction

Relatives frequently provide assistance or care for patients with life-limiting illnesses, and so serve as vital sources of information for them. They have a significant influence on the patient's well-being, care situation, and quality of life, but they are also impacted by the patient's sickness in terms of their own unique burdens and requirements [1, 2]. During the course of the patient's condition, from diagnosis to death, and during grief, a variety of emotional, physical, and economic variables add to the families' burden. The families' psychological load can even outweigh the patient's suffering as the patient approaches death [3]. Palliative care strives to enhance not just the ill person's quality of life, but also the quality of life of their relatives and friends. However, compared to the patients' wants and concerns, far less is known about the family. A growing number of studies have focused on the challenges and demands of relatives and family caregivers during palliative and hospice care, as well as during bereavement [4]. In addition, preliminary research has looked at supportive strategies for family at various stages of the disease [3]. The goal of this book is to give a current review of the literature. A review of recent worldwide studies was conducted in order to gain a better understanding of relatives' issues and requirements during palliative and hospice care for patients with life-limiting illnesses.

Materials and methods: This narrative review includes all relevant peer-reviewed publications published within the last two years on 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 with advanced incurable diseases throughout the disease trajectory. Excessiveness was avoided by excluding studies concentrating on relatives' issues and requirements during grieving due to the wide range of topics covered. The term "relatives" was used in this research review to cover friends, family, and informal carers of patients. All sorts

of incurable and/or severe illnesses, as well as all types of palliative or hospice care arrangements, were included.

Relatives psychological morbidity and burden: Suffering from Psychosocial Distress High levels of psychological anguish have been documented before in the literature, and three additional studies have confirmed these findings, revealing high or significant levels of psychosocial distress in 66-96% of family caregivers in various palliative care settings. In their pilot study, Ullrich investigated distress-causing situations using a modified problem list from the Distress Thermometer [5], with melancholy, grief, and weariness being the most prevalent (80-83 percent). Larger levels of distress appear to be linked to a higher number of unmet requirements and dissatisfaction with patient treatment [5], in addition to previously described concerns.

Symptoms of Anxiety and Depression Moderate to severe anxiety and depression were present in 43 percent and 41 percent of family caregivers of advanced cancer patients, respectively, at admission to a palliative care ward, which is consistent with two larger new studies: Dionne-Odom et al. reported rates of 23 percent for high depression and 34 percent for borderline or high anxiety in 294 family caregivers of advanced cancer patients [6], and Goetze et al. reported high anxiety levels of 32 percent in 294 family caregivers of In 112 family caregivers of patients with terminal cancer, Areia et al. discovered a high risk of

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anxiety in 72 percent and a high risk of depression in 69 percent using various measures. Furthermore, 51% of family caregivers [7] reported 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 non-colorectal gastrointestinal cancer in a randomised controlled research. Patients reported higher depression symptoms, whereas caregivers reported more anxious symptoms, according to the findings. Anxiety and depression symptoms in dyads were shown to be positively related [8]. Younger age, female gender, relationship to the patient, the caregiving role played, satisfaction with health care professionals, shorter nighttime sleep, less physical activity, family functioning, and low engagement in self-care practices were all associated with family caregivers psychological morbidity. In 173 carers of advanced lung cancer patients, death fear was linked to dysfunctional attitudes.

(Psychological) Burden as a Whole Anxiety, sadness, patient age, gender, and changes in meaning all appear to influence overall psychological load in families. Williams et al. revealed in a qualitative research that the stress of female family carers might also be induced by adherence to stereotyped gender norms that impact women as main caregivers [9]. Family caregivers' self-efficacy was found to be the biggest indicator for their psychological load along the patients' whole illness trajectory in patients with newly diagnosed lung cancer. In 50 informal carers of patients with advanced cancer, perceived competence, resilience, and positive elements of caring were the strongest predictors of burden. The Importance of the Care Setting and the Use of Assisting Services The psychological burden appears to be associated with managing the patients' psychological or psychiatric symptoms in family caregivers of patients receiving palliative or hospice home care, as mediated by caregivers use of escape-avoidance coping responses, their own poor health status, and being the patient's spouse. According to Kobayakawa et al., 11% of carers have visited psychiatrists or psychologists to learn how to manage the patients' symptoms, and another 11% stated the desire/plan to do so [10]. According to a major study of 373 cancer patient carers, assisting with medical care was linked to increased emotional and psychological strain, whilst assisting with non-medical matters was linked to increased psychological burden and harmed the relationship with the patients. Direct patient care activities raised load while improving connections with patients, but the use of assistance had mixed effects on burden.

Discussion

With 64 new publications focusing on the period during the patient's disease trajectory, this narrative review demonstrates the impressive amount of new research on psychosocial and existential problems, supportive needs, and potential interventions for relatives of patients with life-limiting diseases. The review comprised 62 original research publications (73 percent of which were cancer-related) and two reviews from the past 24 months. The rapidly expanding number of publications on this topic shows a growing awareness of the need of including patients' family in palliative and hospice care perspectives and activities. The research offered here look at many various areas of relatives' problems and demands, showing the vast range of issues that impact relatives. The formation of a full image of the relatives' position is now complicated by the several distinct and heterogeneous factors. The studies presented not only covered a wide range of topics, but they also looked at different target groups (relatives, family caregivers, families and friends, informal caregivers, family carer, carer, etc.) and looked at different care settings in various life-limiting diseases at various stages and with various cultural backgrounds. Very different sets of putative

risk variables have been investigated in the context of those research, making it difficult to compare results. Many of the research are cross-sectional, and the few longitudinal studies have looked at different time periods. Furthermore, vocabulary is used and interpreted differently between research, for example, the phrases "burden" and "psychological morbidity." Furthermore, certain notions, such as "quality of life," were assessed and interpreted in a variety of ways. Finally, for quantitative evaluations, a variety of measures and instruments were utilised, with some of the questionnaires not having been verified for their specific reasons.

Conclusion

In conclusion, psychological and existential difficulties, as well as the supporting requirements of family of patients with life-limiting conditions, are clinically significant throughout the course of the patient's sickness and should not be overlooked in palliative and hospice care. Studies show intricate constructions of many issues, wants, and influencing variables, but there is still a lack of full comprehension of the relatives' condition. On the one hand, more systematic and longitudinal research are needed to better understand their position, while supportive treatments must be created and tested in randomised trials to improve supportive care for families in palliative care and hospice practice.

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Not applicable.

Conflict of Interest

None to declare.

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