

Self-management by the family caregiver in palliative care

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Abstract

Introduction

Palliative care is the answer to the suffering that impacts at various levels in the trajectory of an incurable disease, to improve the quality of life of sick people and those close to them. The family caregiver works together with the multidisciplinary care team to ensure continuity of care and management of the complex therapeutic regimen at home. This with consequent stress/burden, which comes from the ethical implications and decision-making in caring for the well-being of your family member. The self-management advocates specific knowledge and care with a broad therapeutic plan that is harmonized with the individual values and needs of the sick person, assuming a right for themselves and their family members to make informed choices about their health. Recognizing all these aspects led to the design of a research project within the scope of the PhD in Nursing, to expand knowledge about the challenges that family caregivers are subject to, with the aim of improving the nursing intervention.

Aim

To present the design of the research project that aims to understand the lived experience of the family caregiver who manages the therapeutic regimen of their family member in the context of palliative care at home.

Methodology

Van Manen's method of phenomenology of practice proposes steps that support access to pre-reflective experiences in the spheres of the family caregiver's lifeworld. This phenomenological-hermeneutic approach guides the researcher to be aware of his own vision, which also emerges in the literature, to know the other and how he experiences and sees his world through the phenomenological interview, in the sharing of narratives.

As part of the collaborative group of qualitative research in nursing and phenomenology, it was possible to attend seminars aiming to prepare the phenomenological interview, waiting the opinion of the ethics committee. Participants are family caregivers of sick people accompanied by a palliative care team.

In the recommended thematic analysis, the reflective methods of thematization and analysis of meaning will be integrated with the method of epoché and reduction, in order to describe the structure of the phenomenon. Consequently, phenomenological writing will have a vocative dimension, trying to systematically explore the meaning structures of a phenomenon or event.

Throughout the investigation process, ethical principles and recommendations appropriate to the investigation will be respected, confirmed by the opinion of the institutional ethics committee.

Results and Discussion

Based on the multiplicity of points of view, an inclusive or abstract conception is created, trying to significantly increase the conceptualized reality of the phenomenon. Knowing, comparing, and synthesizing multiple realities makes the common realities of each family caregiver more visible, not canceling out the singularities. The methodological options aim to level the phenomenological direction and theoretical framework rigorously.

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Conclusion

The concern with the complex experience of the family caregiver in the self-management in the context of palliative care is multidimensional in the various ethical and practical issues and the overload in caring for the other. Accessing the limitations, emotions and potential of each family caregiver generates relevant knowledge, in which the experience lived in the self-management reaches a particular space for nursing care focused on the family caregiver based on their real experience.

Keywords

Lived Experience; Palliative Care; Self-Management; Family Caregiver.

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