

Abstract

As a nurse in palliative care I have noticed that a gap sometimes exists between the understanding of healthcare professionals and of our palliative-care clients regarding the clients' lived experience and their perception of quality of life under those circumstances. As the main aim of palliative care is, however, to contribute to people's quality of life, I felt impelled to explore the phenomenon from the patients' point of view. The purpose is to provide healthcare professionals with a deeper insight into this experience, and thereby empower them to become more able to support their clients towards a better quality of life.

The research approach was the Vancouver School of Doing Phenomenology, since its aim is oriented towards the construction of understanding by grasping the meaning of a phenomenon. The participants were seen as co-researchers and were selected through purposeful sampling, and the data collection was carried out through dialogues with ten co-researchers with different incurable, life-threatening diseases, a total of fifteen dialogues. The data analysis was thematic.

The study revealed that fatal illness has had deep social, physical and personal effects on the co-researchers, who use a variety of resources to make their lives easier. Increased symptoms often reminded them of the gravity of their disease and provoked anxiety attacks and existential concerns. It transpired that a positive frame of mind, hope and faith, as well as the feeling of having a role and a purpose, had a positive influence on quality of life, and support from family was crucial. Another important factor was whether or not they received adequate social services; most of them felt that pursuing their rights was too cumbersome and complicated, and that it was hard to live on the benefits they received. A professional and supportive approach from healthcare personnel had a positive influence on quality of life, but when health personnel

appeared to be uninterested or rushed, this was discouraging. The co-researchers' need for 'human contact' with healthcare professionals was clear, and their experiences of care from specialised palliative nurses were strikingly positive.

Despite their physical burden and deterioration, and a life 'consisting of getting bad news,' the co-researchers' profound need for going on with as meaningful a life as possible, and in society with others, was clear, and is reflected in the study's overriding theme: 'Remember that I am still alive.'