LIVED EXPERIENCE OF CANCER PATIENTS AND THEIR FAMILY MEMBERS IN A VIEW TO DEVELOP A PALLIATIVE CARE GUIDELINE FOR THE NURSING PERSONNEL

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Alleviating the problems faced by patients in their advanced stages of cancer and their families has drawn substantial public attention, but little is known about the experience of these people.

Objectives of the study
- To elicit the lived experience of cancer patients
- To elicit the lived experience of their family members.
- To identify the needs of cancer patients and family members for developing a palliative care guideline for the nursing personnel.

Methods A phenomenological approach using descriptive analysis was utilized to explore the human experience of the phenomena under scrutiny. Interviews were recorded and verbatim were transcribed, and they were manually analysed. The Colaizzi methodological approach was used.

Results The 10 themes identified for the cancer patients were: all change, feeling of helplessness and hopelessness, uncertainty, wishing to fulfill their role, accepting loss of control, feeling of becoming a burden, fear of death and loss, desire to live, wish to be with dear ones, developing trust in god’s plan. The essence of the phenomenon, experience of living with cancer, was to regain a control over the existential changes i.e. the situation and one’s own body. The 6 themes identified for the family members of the cancer patients were questioning god, living with fears and uncertainty, issues related to happiness, feeling of added responsibility, ensuring best possible treatment and care and confronting negative feelings. These six themes gave a structure presenting the essence: balancing a changed life situation in fear and uncertainty.

Conclusion The results of this study challenge nurses to be conscious of the nature and difficulties that not only patients face but also family members are encountering. The study can increase the understanding of what it is like to have cancer in its advanced stage.