SELF-PERCEIVED BURDEN TO FAMILY IN TERMINALLY ILL CANCER PATIENTS AT PALLIATIVE CARE UNIT IN JAPAN: PERSPECTIVES OF PATIENTS

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Self-perceived burden (SPB) is a common problem in terminally ill cancer patients. SPB affects decision making such as life-sustaining treatments, choosing care facilities and communication between patients and the family at the end of life. However there are few studies clarifying SPB. The purpose of this study were to describe the experience of SPB in terminally ill cancer patients at palliative care unit in Japan, and to obtain what patients need medical staff to do to relieve SPB. Semi-structured interviews were conducted in five patients.

Two investigators were involved in answer interpretations to fully understand the meaning of participants' insight and reduce bias. Participants are all male in the age range of 63-73 and retired. The primary caregiver of them was their wife. SPB consists of six following categories 'physically burdening' 'making the family worry' 'making the family feel impotent' 'venting on family' 'affecting family roles' and 'causing problems financially and in the human relations related with admission and death'. Participants hoped that the medical staff cared them and their family, for instance managing symptoms, listening to the patients and their families, making the patients feel comfortable and being faithful to tasks of palliative care. As SPB is constructed from multi-dimensional aspects, it is crucial to assess the patients holistically including the relationship with their families, the patients' role in their families and the families themselves.

This study suggested that nurses should approach not only the patients but also their families, and evaluate the care and attitude continuously.