

Loved ones within palliative care – understanding, strategies and need for support

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ABSTRACT

It is well known that during the palliative process both patient and loved ones have to face, and prepare themselves, for the patient's approaching death. Their daily life will be marked by the disease, and physical, social, psychological and existential questions will arise. Increased knowledge about being a loved one involved in palliative care could provide important guidance for the professional staff to enabling them to support the loved ones in finding new ways of living after the patient's death. The aim of the thesis was to increase knowledge of what it can be to be a loved one involved in palliative care from the perspective of understanding what is going on, strategies used and support needed.

The studies used both qualitative and quantitative methods, in the form of in-depth interviews and questionnaires with open-ended questions. Descriptive statistics and content analysis were used, in the analysis.

The results show that the understanding of loved ones depended on information given in various ways during the disease process. The information could be gained either explicitly from health-care staff or implicitly from everyday conversation between themselves and the patient or throughout the progression of the disease.

The loved ones used different types of strategies to cope with the situation and to be able to meet the patient in the current situation. The professional carers opinion was that the more informed and aware the loved ones were about the patient's disease the more they were able to cope with the situation. Information was helpful both in preparing for and during the bereavement. Need for support after the patient's death, depended on how they managed the bereavement process, together with the kind of relation they had had with the dead person. The personal network was the most important source of support in contrast to professional support which was mainly needed when the personal network for some reason failed or when the grief became complicated. The professional carers opinion was that they could provide the support the loved ones needed during the patient's hospital stay but rarely after the patient had died.

The healthcare system has to find methods to support the loved ones both during the time of the patient's illness as well as during the bereavement process, for those who need such support.

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This thesis is based on the following papers:

- I Benkel I, Wijk H, Molander U. **Managing Grief and Relationship Roles Influences Which Forms of Social Support the Bereaved Needs.** *American Journal of Hospice and Palliative Care.* 2009;26:241 -245.

- II Benkel I, Wijk H, Molander U. **How loved ones obtain information about the progress of the patient's cancer disease is important for their understanding .** *Submitted.*

- III Benkel I, Wijk H, Molander U. **Using Coping Strategies Is Not Denial: Helping Loved Ones Adjust to Living with a Patient with a Palliative Diagnosis.** *Journal of Palliative Medicine.* 2010;1:1119-1123.

- IV Benkel I, Wijk H, Molander U. **Hospital staff's opinions concerning loved ones' understanding of the patient's disease and need for support.** *Submitted*

- V Benkel I, Wijk H, Molander U. **Family and friends provide most social support for the bereaved.** *Palliative Medicine.*2009;23:141-149.

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