

Patients' quality of life -
Living with incurable cancer in palliative homecare

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What is to live a good life? That we care about the answer to this question is not surprising. For if we choose to live rather than to die, we want our lives to be good ones. But if we do not agree with one another as to what constitutes a good life...Not only do we disagree with one another as to the nature of the good life; often we find that the answers we have given are unsatisfactory even for ourselves...Yet we cannot let the matter rest, so long as we care about improving the quality of our lives. When we ask what it is to live a good life, we are concerned with what is, in many ways, the most important question of all (Smith 1980).

ABSTRACT

My clinical experience is that living in incurable cancer at the end of life is complex to patients and their families. Patients seem to have a rather good quality of life (QoL) but problems related to the progression of the illness constantly challenges and changes QoL. These changes seem to at some points improve or diminish QoL which are distressing to patients and their families. But what meaning do patients give QoL when illness progress? Further, my clinical experience is that QoL assessments are not integrated naturally in the daily care of dying patients and professionals do not ask patients how they apprehend their QoL in general.

The overall aim was to explore how QoL is influenced and its importance for patients living with incurable cancer at the end of life, while being cared for at home with support from family caregivers and a palliative homecare team (PHT). The participants lived in the county Jämtland in the middle of Sweden, and the sample included patients (n=76) who were more or less confined to bed (ECOG PS), cared for by family caregivers (n=4). Mixed methods were used, mainly qualitative methods, analyzed by content analyses. Data collected with quantitative method was analyzed using mainly non-parametric methods.

This thesis consists of four empirical papers (I-IV). Major findings illustrated how complex QoL in fact is and that it was essential to patients QoL to be a part of a daily and social life. The last weeks of life was not a calm transitory phase during which patients, family and professionals had time to adjust emotionally. Further, body and mind became more segregated than at any other time during the transition phase. This is strengthened by paper IV with patients in particular, which provided abundant information on different aspects related to the concept of QoL. Moreover, the quantitative study (I) showed that medical care and QoL could actually improve after patients had been designated to a PHT, despite their progressive disease. The social dimension of QoL was more obvious in the qualitative studies with patients (II and IV) and family caregivers (III), and not at all in the quantitative study (I). The existential dimension on the other hand was more evident in paper I and III than in paper II and IV. In addition, the physical and psychological dimensions appeared equally important in all of the papers.

Findings also illustrated that some patients with incurable cancer did not regard their QoL as being as negative as one might expect. Positive factors that have been identified for potentially improving QoL was receiving optimal support by family caregivers and optimal symptom control, being able to stay at home, and maintaining as normal an everyday life as possible and being regarded as an autonomous individual. The findings in this thesis also point out the necessity for healthcare professionals in palliative care to seriously discuss what issues patients close to death and their families consider as important for providing an optimal QoL.

Key words: Advanced cancer, Assessment of quality of life at the end of life, AQEL, existential, hospital based palliative care, mixed methods, neoplasm, nursing, palliative care, quality of life, social life, support.

ORIGINAL PAPERS

- I Melin-Johansson C., Axelsson B., Gaston-Johansson F. & Danielson E. (2007). Significant improvement in QoL of patients with incurable cancer after designation to a palliative homecare team. (Submitted for publication)
- II Melin-Johansson C., Axelsson, B. & Danielson E. (2006). Living with incurable cancer at the end of life – patients’ perceptions of quality of life. *Cancer Nursing*, 29, 391-399.
- III Melin-Johansson C., Axelsson B. & Danielson E. (2007). Caregivers perceptions about the terminally ill family members’ quality of life. *European Journal of Cancer Care*, 16, 338-345.
- IV Melin-Johansson C., Axelsson B., Ödling G. & Danielson E. (2007). The meaning of QoL as narrated by patients with incurable cancer who received palliative homecare. (Submitted for publication)

The journals in which paper II and III are published has given permission for reprints in this thesis.

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