

Patients quality of life –

Living with incurable cancer in palliative homecare

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The thesis is based on the following papers:

- I Melin-Johansson C., Axelsson B., Gaston– Johansson F. & Danielson E. (2007). Significant improvement in quality of life 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. & DanielsonE.(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 quality of life as narrated by patients with incurable cancer who received palliative homecare. (Submitted for publication)



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ABSTRACT

My clinical experience is that 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? Furthermore, 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.

This thesis consists of four empirical papers (I-IV), and 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.

QoL in general includes four dimensions: the physical, the psychological, the social and the spiritual/existential. Major findings in this thesis illustrated that it was essential to patients QoL to be a part of a daily and social life during the route of the illness. Findings also showed that the last weeks of life was not a calm transitory phase during which patients, family and professionals had time to adjust. Further, body and mind became more segregated than at any other time during the transition phase. This is strengthened by paper IV in particular that showed that patients oscillated between experiencing intense suffering and acquiring breathing spaces in suffering. The quantitative study (I) showed that medical care i.e. getting hold of staff and receiving the care they regarded as appropriate, and QoL in general actually improved after designation to a PHT. The social dimension of QoL i.e. having significant others and being cared for at home 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 spiritual/existential dimension involved in particular what was meaningful in life to patients and related very strong to QoL in general. This was more evident in paper I and III than in paper II and IV. The physical dimension involved being alleviated from suffering especially pain and having a physical strength to perform different activities in daily life. Further, the psychological dimension involved the importance of being free from depression and anxiety. Depression also related strongly to QoL in general. The physical and psychological dimensions appeared more or less important in all of the papers.

Major findings also illustrated that some patients with incurable cancer did not regard their QoL as being as negative as one might expect. Other 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.