

INTRODUCTION

The focus of this thesis is patients' quality of life (QoL) when living with incurable cancer, cared for at home with support from family caregivers and a palliative homecare team (PHT).

More than 10 million people in the world are diagnosed with cancer every year. Patients with incurable cancer comprise the largest group in Sweden that is currently offered palliative care at home. Approximately 22 000 people die every year in different cancer diagnoses (Socialstyrelsen 2005). In Sweden patients are supported by different multidisciplinary palliative care teams. The aim is to provide palliation through different interventions. The teams often include nurses, physicians, physiotherapists, occupational therapists, and chaplains. However, the access of palliative home care varies locally. Palliative care aims at providing the best possible QoL to patients until the time of death (World Health Organization 2002). However, QoL changes during the course of the cancer illness and critical moments are described in four phases: the diagnosis, completion of first treatment, recurrence and transition from active treatment to palliative care. There are also three possible goals to consider when treating patients with cancer, curing the disease, increasing survival time and improving QoL (McIllmurray *et al.* 2001).

My clinical experience is that living with incurable cancer at the end of life creates a complex situation for both patients and their families. Patients seem to have a rather good QoL but problems related to the progression of the disease constantly challenge and change QoL. These changes seem to improve or lower QoL at certain times, which is distressing to patients and their families. But what meaning do patients apply to QoL when the illness progresses? Moreover, QoL assessments are not integrated naturally in the daily care of dying patients and healthcare professionals do not ask patients how they apprehend their QoL. According to Jocham, Dassen, Widder-shoven & Halfens (2006) there is little evidence regarding the actual meaning of QoL, and there are no systematic standards of assessing the outcome of QoL for patients in a palliative care setting. Further, patients with incurable cancer are vulnerable and often redraw from participation (Waldron *et al.* 1999). In addition, Rummans *et al.* (2000) emphasize that if QoL is neglected this will lead to more suffering for patients and consequently may even hasten death.

In this thesis, adult patients living in Sweden with incurable cancer at the end of life were investigated about how they perceived QoL. Focus was on how the patients described QoL as their illness progressed. Health is sometimes described as synonymous with QoL in literature (Anderson & Burckhardt 1999). Health related quality of life was not investigated as it is primarily a medical term used as an outcome measure (Moons, Budts & De Geest 2006), and fading health does not essentially result in health becoming the most important issue for patients with incurable cancer (Waldron *et al.* 1999). QoL is broader and more complex than health related quality of life and includes many different dimensions of being (Cooley 1998). In this thesis patients' different descriptions of QoL are integrated with family caregivers' descriptions of the ill family members' QoL, as well as the use of mixed methods. In this way the QoL for patients living with incurable cancer was explored from different perspectives in order to achieve a more profound understanding of the meaning of QoL.

REVIEW OF THE LITERATURE

In this review of the literature QoL is described from a general point of view. After this description a model is presented that visualizes one general idea of QoL. This is followed by a review of QoL in patients living with incurable cancer, including four dimensions of QoL. Thereafter, palliative homecare, patients with incurable cancer at home, family caregivers' views and palliative homecare teams are described.

Quality of life

QoL is a complex and elusive concept that is commonly studied by social scientists, psychologists and healthcare professionals (Haas 1999a). Reflections over the good life were documented about 360 years before Christ by Plato, and his student Aristotle said that to be happy is to live well (Tatarkiewicz 1976, p.4). In the middle of the last century the World Health Organisation (WHO) introduced the QoL concept when defining health as “a state of physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO 1947). But it was not until thirty years later, 1978, that WHO stated that all individuals have a right not only to physiologic care but also to a psychosocial care and an adequate QoL (Cooley 1998). In a review by Moons *et al.* (2006) it was reported that between 1966 and 2005 about 77 000 articles related to QoL were published, and the amount of QoL articles started to increase considerably from 1989. The concept QoL has been an important element in research and clinical practice since early 1970s for evaluating the quality and outcome of health care. In the 1980s different gap in theories were proposed between current hopes and expectations and the individual's present experiences (Calman 1984). Despite development of the concept there is still no consensus about how to define QoL. Dedhiya and Kong (1995) state this could be due to the fact that QoL is a vague term and lacks focus. At the same time it provides hope and helps give life a meaning. Moons *et al.* (2006) add that the concept includes negative as well as positive aspects. Holmes (2005) argues that the lack of consensus about the definition and meaning of QoL makes it difficult to assess. In fact Holmes (2005), question if QoL is at all possible to measure. Farquhar (1995) suggested that in order to reach a consensus about QoL not only experts but also laymen must be included in the discussion. However, there is a consensus that QoL encompasses physical, psychological, social and spiritual dimensions (Haas 1999a, 1999b), based on patients' perceptions (Haas 1999a, 1999b, King *et al.* 2002). Therefore, distinguishing what

contributes to QoL is a multifaceted undertaking, as different people value different things (Edlund & Tancredi 1985). Furthermore, Wrosch and Scheier (2003) argue that QoL is affected by personality. Optimists deal with their life situation in a different way than pessimists.

A quality of life model

A model of QoL was utilized as a guide in this thesis in order to acquire a coherent view of the physical, psychological, social and spiritual dimensions of QoL (Figure 1). The model illustrates the work of Haas (1999a, 1999b).

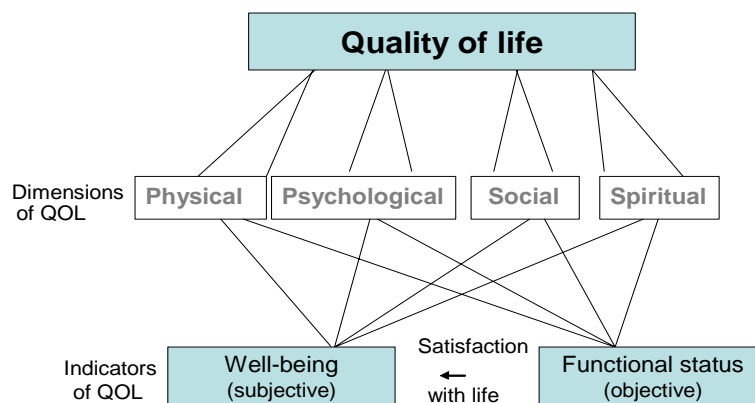


Figure 1. Quality of life model according to Haas (1999b p. 219) used with permission from Journal of Nursing Scholarship.

Haas (1999b) clarified that QoL is value based, multidimensional and dynamic, and includes some kind of assessment or measurement. The subjective or well-being component is the primary indicator of QoL and affects all four dimensions of QoL. Satisfaction in life is another important indicator of QoL, which affects the sense of well-being. Both well-being and satisfaction with life are important components of QoL but Haas means that they are not synonyms with QoL. When assessing QoL an evaluation should be performed covering all four dimensions. It is not sufficient to assess only the physical dimension and then come to conclusions about patients' QoL. Haas' definition of QoL is:

QOL is a multidimensional evaluation of an individual's current life circumstances in the context of the culture and value systems in which they live and the values they hold. QOL is primarily a subjective sense of well-being encompassing physical, psychological, social and spiritual dimensions. In some circumstances, objective indicators may supplement or, in the case of (people) unable to subjectively perceive, serve as a proxy assessment of QOL (1999b, p. 219).

In conclusion QoL is an evolution of a person's current life conditions and is always present even if it differs from alleviated to low or between good and bad (Haas 1999b).

Quality of life in patients with incurable cancer

In some cultures it is taboo to talk about cancer, even though silence and shame regarding cancer was more common in the past (Ashing-Giwa *et al.* 2004). A culture is the result of different mechanisms influenced by subjects and environmental stimuli, shaped by the values, beliefs, norms, and practices (Davidhizar & Gigar 2004). Further, a culture shapes beliefs and behaviors about disease and is distinct from illness in the way that it is a pathological state linked to an organic disease. A disease can be labeled with a diagnosis but pay no attention to what it means to live with a disease. Illness on the other hand is a subjective experience of being unwell and do not always relate to an organic disease. Experiences of illness can be narrated by the ill person and in that way the meaning of illness may be understood (Payne, Seymour & Ingleton 2004). According to Cella (1994) QoL issues are important at all stages of the cancer journey but are most important during the final phase of incurable cancer. Yet little is known about the QoL in this phase (Lo *et al.* 2002).

In a retrospective analysis of case notes of patients with incurable head and neck cancer treated in hospital, physical symptoms were documented but psychosocial and spiritual aspects were not (Ethunandan *et al.* 2005). Lund Hagelin, Seiger and Furst (2006) found that patients scored low in QoL when admitted to a palliative care service unit and that QoL deteriorated with approaching death. Further, it was stated in a review that patients' perceptions of QoL can be influenced by their expectations and fears concerning the future (Ferrell 1996). Sahlberg-Blom, Ternstedt and Johansson (2001) found that even if patients scored low on QoL in contrast to people in general they felt happy and satisfied at the same time. Steele, Mills, Hardin and Hussey (2005) found that patients with incurable lung cancer scored good to very good on QoL when admitted to hospice care.

Certain dimensions are described in the literature as being central to patients' QoL when living with incurable cancer and are described below.

Different dimensions of quality of life

In this section, patients' experiences when living with incurable cancer are described, as is the term QoL in general, regardless of the setting, with help of Haas' QoL model (Haas 1999b). Four dimensions are described as central in the model: the physical, the psychological, the social and the spiritual.

Physical dimension

Progressive illnesses such as cancer often involve a cluster of symptoms influencing each other (Ferrell 1996, Fitch 2005). One of the most prevalent symptoms among more than 50 % of patients with a terminal illness such as cancer is pain (Weiss, Emanuel, Fairclough & Emanuel 2001, Solano, Gomes & Higginson 2006). Pain or the fear of pain and suffering is characteristic for patients (Osse *et al.* 2002). It overshadows all other symptoms and is most frequently reported and prioritized by cancer patients (Boström, Sandh, Lundberg & Fridlund 2004, Strömgren *et al.* 2006). In a review by Strang (1998) it was concluded that cancer pain has a negative effect on patients' physical, emotional, and existential dimensions of life. McCarthy *et al.* (2000) found in a retrospective study with 1459 terminal ill cancer patients, that almost half of them experienced severe pain during the last three days of life. Patients experience pain as something horrifying and they both reveal and conceal experiences of pain. On the other hand, controlling pain with continuous pain management made pain seem less important and improved patients' QoL (Vig & Pearlman 2003, Larsson & Wijk 2007).

Fatigue is another common physical symptom among cancer patients (McCarthy *et al.* 2000, Strömgren *et al.* 2006), and has a great impact on daily life, including QoL (Von Roenn & Paice 2005). Some factors that may contribute to fatigue are the cancer itself, treatment, medication, complications or other physical or psychosocial factors (Barnes & Bruera 2002). McCarthy *et al.* (2000) found that patients' functional status as well as QoL deteriorated during the last six months and they became more dependent on others regarding personal activities. Other common symptoms are constipation, confusion, nausea, vomiting, and dry or sore mouth (Fitch 2005). In the last weeks of life breathlessness, increased pain and delirium are common (Plonk & Arnold 2005). Other terminal signs are loss of appetite or anorexia and cachexia, including weight loss (Plonk &

Arnold 2005, Von Roenn & Paice 2005, Hopkinson, Wright & Corner 2006, Strömngren *et al.* 2006). At an advanced state in the illness weight loss becomes a complication and predicts a poor prognosis (Von Roenn & Paice 2005). According to Ferrell (1996) physical well-being for cancer patients, irrespective of the stage of the disease, incorporates relief of symptoms, maintenance of function and autonomy.

Psychological dimension

Apart from physical symptoms patients with incurable cancer most often experience psychological distress at the same time and when approaching death pain and psychological distress increase (McCarthy *et al.* 2000, Von Roenn & Paice 2005, Tsai *et al.* 2006). Depression affects about one in four patients and is significantly related to QoL in general (Smith, Gomm & Dickens 2003, Lloyd-Williams, Dennis & Taylor 2004), and is negatively influenced by pain, and depression also predicts anxiety (Mystikado *et al.* 2006). Patients themselves often report and prioritize depression (Osse *et al.* 2002, Fitch 2005, Strömngren *et al.* 2006, Wilson, Chochinov, Skirko *et al.* 2007) but depression is found to be a hidden symptom as patients do not fully describe their depressive symptoms (Lloyd-Williams 2003). King, Heisel and Lyness (2005) emphasize that in many patients depression goes undetected and consequently untreated. Depression may even prevent patients from adjusting to an illness (Lynch 1995). Unrelieved symptoms such as pain, fatigue, immobility, or nausea may cause depression and reduce social, cognitive or emotional functioning and consequently affect QoL in general (Smith *et al.* 2003, Lloyd – Williams *et al.* 2004, Mystikado *et al.* 2005). Few studies have explored the psychological distress experienced by terminally ill patients with cancer (Akechi *et al.* 2004), and the quality of research is also poor in this field (Hotopf, Chidgey, Addington-Hall & Ly 2002).

A common adjustment disorder is posttraumatic stress and has been recognized in adult cancer survivors (Smith, Redd, Peyser & Vogl 1999), but not in any of the 209 terminally ill patients with cancer in a study by Akechi *et al.* (2004). Fear is another common stressor e.g. the fear of pain, of being alone at night or fear of death (Osse *et al.* 2002, Fitch 2005). Terminal delirium, confusion and agitation are other stressors during the last days of life (Shuster 1998, Von Roenn & Paice 2005). In order to deal with different stressors patients often use combinations of coping strategies during the illness trajectory (De Faye *et al.* 2006), and experience positive feelings from time to time in spite of suffering from incurable cancer (Van Der Lee *et al.* 2005). Ferrell (1996) concluded that psychological-wellbeing is about searching for control when facing death, emotional distress,

changed life priorities and fears of the unknown, as well as recognizing positive changes in life.

Social dimension

Social support requires relationships. Important networks for patients are their family, who are the most important and who provide tangible and affirmative support; friends, e.g. friends with cancer serve as role models; and healthcare professionals who can provide explanations and open communication (McIllmurray *et al.* 2001, Tang, Aaronson & Forbes 2004, Fitch 2005). Patients' need for information is greatest the time of diagnosis and start of treatment, but they also need a continuous flow of information regarding the prognosis and further treatment (Kirk, Kirk & Kristjanson 2004, Finney Rutten *et al.* 2005). For example Gaston and Mitchell (2005) found in a review that the sicker patients became the less interest they showed in being involved in decisions related to the disease. Fallowfield *et al.* (2002) stated that it is always preferable to tell the truth to patients and their families instead of trying to conceal information because it is less desirable.

Sometimes patients' relations to others deepen during the progression of illness but then again relations can become tinged with distress and nervous tension (Block 2006, McLean & Jones 2007). Distress can be caused by financial problems (Nosowska 2004), sexual intimacy is sometimes affected by illness (Stausmire 2004), and even abuse may take place in the family (Fisher 2003). Some patients also avoid talking about the progression of their disease with spouses in order to spare their feelings (Osse *et al.* 2002). Emotional and affirmative support is important to patients, e.g. like feeling appreciated and knowing that they can share their thoughts and feelings (Greisinger *et al.* 1997). Social relations are in general important to patients' QoL (Stewart, Teno, Patrick & Lynn 1999, Vig & Pearlman 2003), that prevent feelings of isolation and meaninglessness (Hunter, Davis & Tunstall 2006), but do not have a significant effect on symptoms such as fatigue, pain, or emotional well-being (Smith, Avis & Assman 1999b). Cooley (1998) emphasized that the relation patients have with their family and the meaning it generates is underestimated in several studies.

The place of death is influenced by the extent of social support patients can receive from family members, living arrangements and marital status (Gomes & Higginson 2007). In Sweden death at home is uncommon, and many patients die alone or separated from spouses (Jakobsson, Johnsson, Persson, & Gaston-Johansson 2006). According to Ferrell (1996) focusing

on social well-being provides an opportunity to observe the person with cancer, their role and relationships, instead of only concentrating on the actual disease.

Spiritual dimension

In the section on spirituality I also included existential issues, as this is of special importance in palliative care. Chochinov (2006) emphasized in a review that the common view in palliative care of spirituality and existence is that human beings have an intense desire to infuse life with meaning, purpose and hope. According to Strang, Strang & Ternstedt (2001) patients diagnosed with cancer are satisfied with the physical care and treatment provided but they are dissatisfied with the spiritual support, or indeed the lack of it. There is also a need to communicate existential issues with healthcare professionals' (Bolmsjö 2000, Strang *et al.* 2001).

The concept spirituality has been criticized as being an unnecessary, poorly defined concept, which is not linked to any specific theory and is used contradictorily in texts (Salander 2006). According to Fitch (2005) spirituality helps patients with life threatening illness to try to make sense of the world and to relate to nature, self and others. At the same time spirituality is challenged (Fitch 2005), and spiritual thoughts are not uncommon as patients strive to comprehend, manage and find meaning in illness (Strang *et al.* 2001). According to Mytko and Knight (1999) including spirituality and religiosity measures in QoL studies provides an understanding of the integration of mind, body and spirit in cancer care. Breitbart (2007) asserted that spirituality does not always need to be linked to religiosity as it is possible for humans to be spiritual but not religious. In a meta-analysis by Sawatzky, Ratner and Chiu (2005) it was found that spirituality is related to QoL but is not a reliable indicator of QoL. Therefore spirituality is best seen as a unique phenomenon conceptually distinct from QoL. Spiritual and religious beliefs help patients to cope with illness and potentially increase their QoL (Greisinger *et al.* 1997, Mytko & Knight 1999).

Nelson, Rosenfeld, Breitbart and Gailletta (2002) showed that religiosity was not related to spiritual well-being but on the other hand it was related to depression. This was due to the anger that patients felt towards God who had caused so much pain. Hills, Paice, Cameron and Shott (2005) found that the feeling of being punished or abandoned by God related to distress, confusion, physical and emotional well-being as well as QoL. In addition it was found that it is essential to patients not to lose faith in God or religion (Norum, Risberg & Solberg 2000, Osse *et al.* 2002). Stefanek, McDonald

and Hess (2005) emphasized that it is too early to decide what role religion or spirituality plays in QoL outcomes related to cancer. On the other hand, Tarakeshwar *et al.* (2006) mean that having religious faith is important to patients QoL.

Existential issues are important to patients in late stage cancer (Griffiths, Norton, Wagstaff & Brunas-Wagstaff 2002), and for how they experience QoL (Cohen, Mount, Strobel & Bui 1995, Ross 1995). Sources of existential distress often concern different losses. For example the loss of functions (Strang 2002), control, social role functioning, continuity, relations, independency and the future (Morita, Tsunoda, Inoue & Chihara 2000, Morita *et al.* 2004, Murata, Morita & Japanese Task Force 2006). Other sources of distress are a changed personality and anxiety for death, (Strang 2002), dependency and feeling emotionally irrelevant (Morita *et al.* 2000), or uncompleted life tasks and acceptance/preparation (Morita *et al.* 2004).

Chochinov (2006) found that what is clearly evident in research concerning dying patients are feelings of hopelessness (e.g. meaninglessness), the loss of their sense of dignity and the fear that they will become a burden to others. Meaninglessness is the essence of existential distress (Morita *et al.* 2000). On the other hand, finding and maintaining a meaning in life (Greisinger *et al.* 1997, Cole & Pargament 1999, Iglesias 2004, Breitbart Gibson, Poppito & Berg. 2004), obtaining feelings of peace (Breitbart 2002) and hope are all of the utmost importance to patients (Benzein, Norberg & Saveman 2001, Morita *et al.* 2004). Meaningfulness is also very strongly related to QoL (Axelsson & Sjöden 1998). Finally, Ferrell (1996) points out that spiritual well-being implicates having the ability to maintain hope and obtain a meaning in life when living with cancer, involves issues of transcendence and is improved by a person's religion and other sources of spiritual support and comfort.

PALLIATIVE CARE AT HOME

The term palliative care is consistent with care given to patients with life-threatening diseases. The purpose is to improve patients and their families QoL through prevention and relief of suffering by early identification, flawless assessment, control of pain and other physical problems as well as psychological, social and spiritual problems (WHO 2002). In spite of this rather new definition WHO has not included existential problems that may occur when living with life-threatening illness. Palliative care at the end of life is consequently provided in the late phase of the disease, and end of life care is one important aspect in the continuum of palliative care. This phase is generally brief; at the most it lasts for a couple of months (SOU 2001: 6). The purpose of palliative care is to identify and control symptoms, to help patients to live in the best way possible despite their illness (Kuebler, Lynn & Von Rohen 2005), and to support involved family members. In a study by Cannaerts, Dierckx de Casterle' and Grypdonk (2004) it was found that the palliative care provided focused on optimizing QoL, and on life not death. Under supportive conditions life was elevated from the illness by creating space to live (e.g. symptom control) and by filling this space with life (e.g. seeing the patient as the norm). According to Thompson and McClement (2002) palliative care acknowledges that individuals are an integrated whole rather than a series of separate parts or states of disease, and that they strive for optimal function despite the closeness to death.

In Sweden the first model for advanced care in patients' own homes was established in 1977 (Beck-Friis & Strang 1993), and currently more than 60 palliative home care teams are established in several parts of the country. In spite of this most patients with cancer are cared for and die in hospital (SOU 2001:6). Patients at the end of life are often offered palliative care at home, in accordance with their wishes and with support from relatives and health care professionals (Lamb 1992, Wennman-Larsen & Tishelman 2002). Care at home, in hospices, and in nursing homes is described as "primarily nursing oriented care cultures" in contrast to emergency care facilities that are defined as "primarily medically oriented care cultures" (Sahlberg Blom 2001, p. 17). Furthermore, advanced homecare is described as "care that replaces hospital care" (SBU 1999, p. 63). Home care is seen as being the care given by healthcare professionals to a patient living at home with the intention of providing and maintaining the best possible QoL (Thomé, Dykes & Hallberg 2003).

Patients with incurable cancer living at home

Living with incurable cancer facing death is exceptionally stressful and complicated. Patients experienced that it was extremely difficult to cope with dying and death and their needs quite often go unattended (Carter, MacLeod, Brander & McPherson 2004, Morita *et al.* 2004). Bingley *et al.* (2006) concluded in a review that when facing death from cancer there is a need to express certain reactions, such as fear, anger, confusion and sadness, and patients must be able to find a meaning with the illness, in order to endure treatment and the effect it has on their body image.

Practicalities of daily living were found to be important to patients with incurable cancer. Patients at home experienced specific problems, e.g. they find it difficult to deal with heavy housework, their limitations in physical performance, coping with an unpredictable future, and living with the fear of developing metastases (Carter *et al.* 2004, Osse *et al.* 2005). Other problems that emerged were financial worries and difficulties in handling certain situations (Osse *et al.* 2002, Fitch 2005). Patients also have varying demands regarding information e.g. pertaining to pain management, fatigue, and palliative homecare recourses (Osse *et al.* 2002, Wong *et al.* 2002). Patients' greatest problems were related to functional well-being and the least of their problems with social and spiritual well-being (McMillan & Weitzner 2000). On the other hand, Francke (2000) states that even if symptoms are controlled and reduced psychosocial and spiritual problems remain. Carter *et al.* (2004) found that addressing existential questions, such as meaning in life was prioritized by patients. Bingley *et al.* (2006) found that death and dying is deeply personal and rarely discussed with healthcare professionals. Patients preferred to discuss death and dying with chaplains or a priest. According to Vooght *et al.* (2005) QoL becomes more important the closer a patient is to death.

Higginson and Sen-Gupta (2000) concluded in a review of qualitative studies that most patients preferred to die at home, always mindful of the fact that home care often needs complementing by in-patient care to maintain optimal QoL (Hinton 1994). Appelin and Berterö (2004) found that patients experienced that palliative care at home provided a sense of security, i.e. patients felt safe and were close to relatives and personal things at home even if the progression of the disease caused insecurity in their life situation. Several studies have reported that patients receive comparatively good symptom control on admittance to palliative homecare programme, with the exception of symptoms such as dyspnoea and confusion (Mercadante, Casuccio & Fulfarò 2000). Patients and relatives were rarely critical of care given at home, on the contrary they felt that they

received excellent care and they felt secure (Hinton 1994). Family life is a key component of patients' QoL and when a patient does not connect with their family this can cause emotional distress (Greisinger *et al.* 1997, Spiroch, Walsh, Mazanec, & Nelson 2000).

Family caregivers' views

Healthcare professionals or family caregiver are not usually involved as proxy ratings or used as stand-ins with incurable patients when assessing patients condition. They are more commonly involved in e.g. patients with dementia (Bryan *et al.* 2005). Few studies that are described in the literature about proxy ratings and patients with cancer have had focus on how reliable proxy information is in comparison to patients' own reports of QoL (Sneeuw *et al.* 1997, Milne *et al.* 2005, Tang 2006). In a literature review by von Essen (2004) the extent of agreement between patients' and caregivers' reports depended on methodological limitations and the specific QoL dimensions studied. Agreement is usually higher regarding tangible issues such as mobility or self-care, and lower concerning patients' experiences of pain or depression. On the other hand, agreement between family caregivers and patients concerning symptom distress and symptom occurrence is more congruent than it is with nurses (Broberger, Tishelman & Von Essen 2005), or physicians (Oi-Ling, Man-Wah & Kam-Hung 2005). Engelberg, Patrick and Curtis (2005) found that family caregivers in most part are able to predict patients' first choice concerning symptoms, preparation for end of life treatment, and moment of death.

The importance of managing the care giving situation of family caregivers was first described in a thesis by Hull (1989) and by Logan (1990). Family caregivers need social and professional support to help prevent physical and emotional distress (Steele & Fitch 1996, Vachon 1998). However, family caregivers believe that the patients' needs are more important than their own (Stewart *et al.* 1999). In other studies it was found that caring for an ill family member at home strengthened relations (Jo *et al.* 2007, Carlsson & Rollison 2003).

According to family caregivers patients experienced a better QoL when cared for at home with support from a palliative homecare team than those patients dying in hospice care did (Carlsson & Rollison 2003). Family caregivers' engagement in the care of patients was like being involved in dark or light (Andershed & Ternstedt 1998). That is, "being in the dark" family caregivers received no support from healthcare professionals nor were they acknowledged, whereas "being in the light" meant that relations felt secure. Andershed (2006) concluded in a review that family caregivers

thought that it was important that the care of the patients was of good quality. Further, they felt a need to communicate their concerns and how they experienced their situation as caregivers. They also needed information about the care provided to the ill patient, as well as support from healthcare professionals.

Palliative homecare teams

The first hospital based palliative care service in Montreal Canada was opened in 1975 by Dr Balfour Mount. The care provided was interdisciplinary and provided by a team of experts. The purpose of palliative homecare teams is to meet the multiple needs of dying patients and their families (Kuebler *et al* 2005). Higginson *et al.* (2003) reported that in the year 2000 there were over 6 500 teams in 87 countries throughout the world, whose aim it was to alleviate symptoms and psychosocial problems, coordinate care and improve communication between patients, family and healthcare professionals. Finlay *et al.* (2002) and Goldschmidt *et al.* (2006) stated that patients and family caregivers expect palliative homecare teams to have specialized palliative knowledge, and to be flexible and easily accessible at any time of the day or night.

Despite an extensive development of homecare programmes in several countries the effectiveness of these programmes has not yet been validated (Smeenk, van Haastregt, de Witte. & Crebolder 1998). When measuring QoL during the last months or weeks of patients' lives, while receiving palliative care, there are several vital areas to consider, e.g. symptom management, choice and control, dignity, preparation, relationships, care coordination and continuity (Aspinal, Hughes, Dunckley & Addington-Hall 2006). A systematic literature review found no clear evidence that PHT and coordinating nurses had any significant impact on patients' QoL (Salisbury *et al.* 1999). On the other hand, nurses in palliative care have a highly worthwhile mission to accomplish, and this is to ensure a positive QoL for patients at the end of life (Matzo & Sherman 2001). QoL is indeed more in focus here than in any other specific sphere of nursing (Annells & Koch 2001). Home-based palliative care has been found to improve patients' physical and psychological health, as well as their QoL immensely, compared with patients who are admitted to hospital (Peters & Sellick 2006). Finlay *et al.* (2002) indicates that there is a small positive advantage for hospice and palliative care services. Apart from reducing physical and psychological symptoms, the time spent in hospital is reduced and multi-professional teams improve patients' outcomes.

RATIONALE

Living with incurable cancer is extremely stressful and nowadays patients live longer with the diagnosis. Nevertheless, the quality of this survival is unclear. Knowledge regarding QoL is surprisingly inconsistent. There is a current consensus that QoL is multidimensional and subjective but not as to how QoL should be defined. The absence of consensus in defining QoL creates disagreements, and consequently comparisons between studies become difficult, as well as the progress in research.

In summary of the literature review relatively little empirical research has been conducted on what the meaning QoL has for terminally ill patients. Most literature describes e.g. patients' QoL at the time of diagnosis, during their treatment, or of those who have survived cancer. Many studies of QoL are related to specific diseases, e.g. breast cancer or lung cancer. Research related to terminally ill patients is scarce within the social dimension. It is also limited within the spiritual/existential dimensions, as is research on how these dimensions influence patients' QoL. Furthermore, there is little research about how family caregivers perceive the ill family members' QoL during the period of time their incurable cancer is restrained. The review has also shown that many studies measure QoL in one dimension only, e.g. the physical dimension and then draw conclusions on this. Few studies have investigated QoL in general including dimensions other than the physical, such as the psychological, social or spiritual/existential dimensions, in order to acquire a better understanding of the meaning of QoL when living with incurable cancer. Therefore it is of importance to explore QoL in that way.

AIMS

The overall aim was to explore how quality of life 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.

The specific aims in papers I-IV were to:

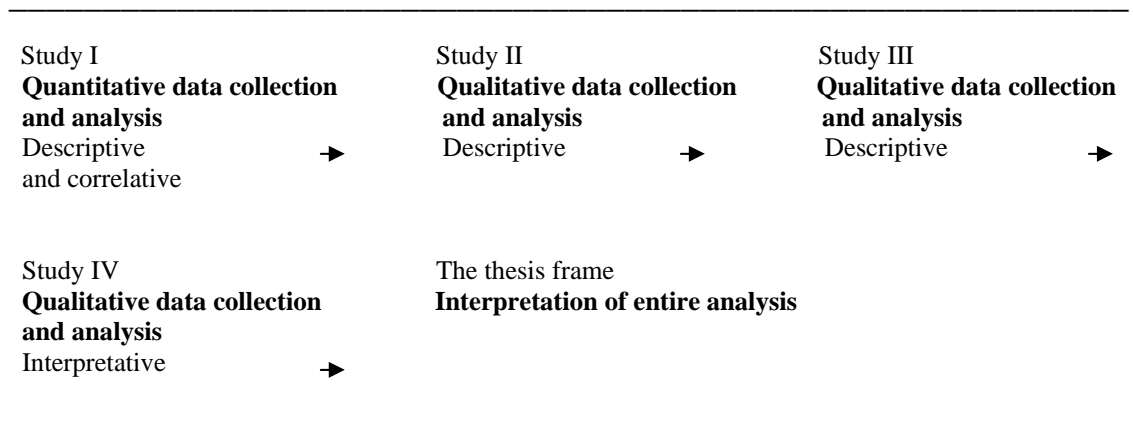
- I Describe and compare quality of life in patients with incurable cancer referred to a palliative homecare team before and after designation, and to identify factors that predict their global quality of life.
- II Describe patients' perceptions of quality of life in incurable cancer at the end of life.
- III Describe caregivers' perceptions about terminally ill family members' quality of life when suffering from cancer.
- IV Elucidate the meaning of quality of life as narrated by patients with incurable cancer approaching death in palliative homecare.

METHOD

Mixed methods were used in this thesis (Creswell 2003), in order to provide better understanding of what QoL meant to patients with different metastasized cancer diagnoses, who were designated to a palliative homecare team. An increasing interest is currently being shown for using mixed methods, which utilize different strategies of investigation collecting data either simultaneously or successively, in order to be able to better understand specific research problems. Data accumulation also entails gathering information using both instruments and interviews. This means that the completed database involves both numerics as well as text information (Creswell 2003).

The purpose with using mixed methods in this thesis was that it was a prerequisite to be able to obtain valid and meaningful answers according to the aims and research questions. Furthermore, it made it possible to acquire a more profound and extensive knowledge of the multifaceted reality patients with incurable cancer must face at the end of life. The intention was also to strengthen the total outcome of this study because the use of qualitative and quantitative methods supplemented each other (Polit & Beck 2004), when exploring the multifaceted reality of patients with incurable cancer at the end of life. In this thesis data were collected and analysed in different steps using in most part qualitative method. Data collection procedure, analysis and interpretation using mixed methods are illustrated in Table 1.

Table 1. The entire data collection procedure, analysis and interpretation using mixed methods.



Data was collected from one questionnaire concerning patients estimated QoL (I), from focus groups with patients (II) and with family caregivers (III). Furthermore, data was collected from narrative interviews with patients (IV). A statistical analysis was performed (I) while a content analysis was used (II – IV). Combining methods in this way unlabeled a more comprehensive understanding of QoL. An overview of the studies is shown in Table 2.

Setting

The hospital-based PHT was established in 1991 and started as a project with one physician and one nurse. Care was at that time provided primarily to patients with incurable cancer who wished to be cared for at home. The purpose of the PHT is to optimize QoL by providing supportive care, by skilled palliative intervention and thereby enable incurably ill patients to stay at home as long as they wish. The palliative interventions include that medical and technical support as well as psychological and social support. In 2004 the PHT proceeded to include other diagnoses than cancer e.g. progressive neurological (e.g. motor neuron disease), lung and heart diseases. Three years later the multiprofessional team consisted of seven full time nurses and three part time physicians. They have specialized training in palliative care and long clinical experience of care in this population. Physiotherapists and occupational therapists employed by the municipalities contribute with their expertise when needed as did social workers and priests employed by the hospital. The PHT is a five-days-a-week unit without institutional beds, working only daytime hours closely collaborating with district nurses who cover nights and weekends. When patients need institutional care they rely on beds in local nursing homes or hospital beds in the appropriate department. The team receives about 250 referrals every year. Annual statistics registered in the PHTs database showed that in 2006 about 140 patients died who were designated to PHT of whom 55 % died at home, 23 % at hospital and 22 % in nursing homes.

Table 2. An overview of the studies I-IV.

| Papers (studies) | Design and focus | Participants n (men/women) | Median age (range) | Civil status | Data collection | Data analysis |
|------------------|---|----------------------------|--------------------|--|--|--|
| I | Descriptive and comparative, changes of QoL after being designated a palliative homecare team, identifying factors predicting QoL | 63 (36/27) | 72 (24-90) | 43 married 16 single 4 married with children at home | Demographic and clinical variables Questionnaire (AQEL) | Descriptive statistics. Non-parametric tests: Wilcoxon Signed Rank Test, Spearman's Rank Order Correlation, Logistic regression analysis |
| II | Descriptive, patients' perceptions of QoL | 5 (2/3) | 65 (54-76) | 2 married 3 single | Demographic and clinical variables Three focus group meetings | Content analysis |
| III | Descriptive, family caregivers' perceptions of the terminally ill patients QoL | 4 (2/2) | 63 (53-73) | 3 married 1 adult child | Demographic and clinical variables Three focus group meetings | Content analysis |
| IV | Interpretative, patients' narrations about their current situation | 8 (6/2) | 56 (35-83) | 5 married 1 single 2 married with children at home | Demographic and clinical variables Narrative interviews | Content analysis |

Participants

The participants all lived in the County of Jämtland in Sweden. Consecutive sampling was used in study I and patients were identified once a week by the author together with the team. In the studies II, III-IV nurses and physicians in the PHT were asked to identify possible participants. Four different samples were used but all eligible patients referred to the team were considered for participation in (I, II and IV). A total of 76 patients participated and all had been diagnosed with different types of metastasized cancer. Patients' functional status was assessed by the team with the Eastern Cooperative Oncology Group Scale of Performance Status

(ECOG PS) grade 1-5 (ECOG 2006). Table 3 shows clinical information regarding the patients.

A total of four family caregivers participated in study III. They all had experiences from living with and caring for terminally ill family members. They were expected to speak of what QoL meant to the ill person from a relative's point of view.

Table 3. Clinical information on patients.

| Papers (studies) | Patients cancer site and metastasis (n) | Patients' median survival time after completion of the study (range) | Patients' ECOG performance status (n) |
|-------------------------|---|---|--|
| I | Breast (4) Prostate (18) Colon (12) Lung (7) Stomach (6) Gynecologic (4) Liver (2) Other cancer sites (10) (n=63) | 3.6 months (1 day – 28 months) | <u>Grade 1.</u> Able to carry out light work tasks (7) <u>Grade 2.</u> Up and about > 50 % of waking hours (44) <u>Grade 3.</u> Confined to bed or chair > 50 % of waking hours (12) |
| II | Breast (2) Prostate (1) Bile duct (1) Bladder (1) (n=5) | 4 months (38 days – 10 months) | <u>Grade 2.</u> (5) |
| III | Breast (1) Prostate (2) Stomach (1) (n=4) | 36 days (0 days-28 months) | <u>Grade 3.</u> (4) |
| IV | Breast (1) Prostate (2) Bile duct (1) Brain (1) Colon (2) Liver (1) (n=8) | 3 months (11 days – 12 months) | <u>Grade 3.</u> (8) |

The inclusion criteria for sampling patients (I, II and IV) were patients who were:

- informed of their diagnosis and prognosis
- aged 18 years or older and spoke Swedish
- lived and received care at home
- graded as 3 (IV) on ECOG PS

Exclusion criteria for studies I, II and IV were patients with:

- expected survival of less than one month, as estimated by the team
- other diagnoses than cancer
- dementia and or other cognitive problems.

The inclusion criteria for sampling family caregivers (III) were:

- caring for a patient who was informed of their diagnosis and prognosis
- aged 18 years or older and spoke Swedish
- caring for an ill family member in their private homes

Exclusion criteria for study III were:

- caring for an ill family member with expected survival of less than one month
- caring for an ill family member with other diagnoses than cancer.

Procedure

Patients with incurable cancer in need of palliative care were referred to the PHT by hospital physicians or GPs. Weekly referrals were assessed by the PHT. Based on patients' medical and/or psychosocial needs the team made decisions regarding designation after which they contacted the patients by telephone to plan their home care. In the quantitative study (I) and in the qualitative studies (II-IV) the PHT nurse in charge registered demographical and clinical data in an investigation record. Patients' functional status was assessed by the team with the Eastern Cooperative Oncology Group Scale of Performance Status (ECOG PS) grade 1-5 (ECOG 2006). All participants (I-IV) were contacted through a letter informing of the purpose of the study, volunteering, interview procedure, confidentiality and informed consent.

Paper I

One hundred and sixty three patients were approached for participation and 63 completed the study. Primary reasons for attrition were that patients were too weak to participate or died before baseline. One week before admission to the palliative team (baseline) the questionnaire, Assessment of Quality of life at the End of Life (AQEL), (Axelsson & Sjöden 1999), information about the study and informed consent in writing was posted to patients who had been referred to the team. The questionnaire was returned by post or collected by the team when they met with the patients in their homes. Two weeks after (follow up) the first AQEL questionnaire was returned a second AQEL questionnaire was posted (follow up).

Paper II and III

Twenty five patients were approached for participation in repeated focus groups and five accepted (II). The main reasons for not participating was that patients felt too weak or too ill, and that they were afraid of what feelings the focus group meetings may awake. Sixteen family caregivers were contacted and four accepted participation (III). The main reason for not participating was that it was difficult for the caregivers to leave the terminally ill person alone at home. Before every focus group meeting participants were contacted by telephone for confirmation about the time and place for the interview. Each focus group met on three separate occasions over a period of four weeks. The interviews lasted for about 90 minutes, were tape-recorded and transcribed verbatim into text. The meetings were carried out at a hospital. A moderator and an assisting moderator conducted the meetings. Each meeting started with several initial questions, followed by three main questions after which follow up questions were asked to facilitate a thorough exploration of each main topic. The meetings were concluded by the participants summarizing the most important things covered.

Paper IV

Twenty eight patients were asked to participate in face to face interviews and eight agreed. The main reason for not participating was that patients were too weak or that they died before the interviews. The interviews were conducted in the patients' home and all except one were lying in their beds. The interviews lasted for about 60-70 minutes, were tape-recorded and transcribed verbatim into text.

Methods for data collection

Questionnaire

QoL was evaluated in study I using the 21 item instrument AQEL (Axelsson & Sjöden 1999). This instrument was developed in Sweden for patients with symptomatic cancer in palliative care. It has been confirmed as being a fairly valid instrument for measuring QoL. The questionnaire have been modified after year 1999 as one question about dyspnoea has been added (see appendix). The response format is a modified analogue scale (AQEL values range 1-10, where 10 is best) and the last question is open-ended. To minimize response bias (e.g. always using the same end of the scale) the direction of the scale varies according to what feels semantically correct. For example when, asking about pain 10 is the worst possible pain, but when asking about QoL in general 10 is the best possible. When data was analyzed items like pain were transformed to the opposite (11 – registered value) making median values closer to 10 always the best regardless of item. AQEL is divided into six dimensions related to physical, psychological, social, existential, medical needs and QoL in general. The physical aspect concerns symptoms such as pain, nausea, and bowel movements, difficulty in breathing, tiredness, and physical activities. The psychological aspect includes sleeplessness, memory, depression, anxiety, and concentration problems. The social aspect includes sharing problems with family, and if family and friends regard the patient as they did before. The existential aspect concerns being able to do what one wants, meaningfulness and joy in life. Variables concerning medical care included patients' perception of their accessibility to healthcare professionals and provision of the care necessary. In addition, at the end of the questionnaire, patients were asked to mark whether the questionnaire was answered at home or in hospital, and whether it was answered independently or with assistance from relatives or health care professionals. The research questions were: What changes in QoL do patients describe after designation to a palliative homecare team? What variables correlate with global QoL? and Which factors predict QoL?

Focus groups

The focus group technique was used in studies II and III. The purpose was to collect as much information on the topic as possible and to hopefully benefit from the facilitating impact of the group dialogue in identifying core components of the concept of QoL specific to incurably ill cancer patients approaching end of life. In focus groups participants are afforded

an opportunity to freely express their perceptions and feelings, and a focused conversation relating to a specific phenomenon is carried out. The intention is not to solve problems, make decisions or reach a consensus (Krueger & Casey 2000). In this thesis the intention was rather to stimulate the participants to interact and communicate with each other and talk about QoL in order to acquire as much and as extensive information as possible about its content. The questions asked in focus groups with patients (II) were: “Please describe what it is like to live with incurable cancer”. “Please describe what you consider meaningful in life”. “When you hear the word QoL what is the first thing you think of?” and in focus groups with family caregivers (III): “Please describe how you comprehend what it is like for the ill person to live with incurable cancer”. “Please describe what you consider as meaningful and not meaningful in life for the ill person”. “When you hear the word QoL what do you think it means to the ill person?”

Narrative interviews

The purpose in study IV was to acquire an even more profound understanding about the concept QoL and its meaning for patients with incurable cancer. According to Mishler (1986) a research interview is a form of conversation in which the interviewer and interviewed interact by “talking together”. That is, the conversation is mutually created by the interviewer and interviewed (Mishler 1986). In this thesis it was important, prior to the interviews, to think about how patients should be approached during the interviews. For example the interviewer’s attitude, how the interview question may influence the patients’ narratives and how to adjust silences and responses are issues that must all be carefully considered. One general question was asked in this study “Would you please describe how you experience your current situation?” To clarify and investigate experiences further follow up questions were asked e.g. “what do you think?” or “how do you feel?”

Methods for analyses

Statistical analysis

Analyses in study I were conducted using the SPSS version 12. Descriptive statistics were used to describe single variables in the questionnaires including patients’ age, gender and civil status. Since the QoL data was ordinal and skewed, non-parametric tests were used in analyses of change

between baseline and follow-up. Non-parametric tests rank/order and classify scores regardless of the shape of the population, and the central tendency median is used (Siegel & Castellan 1988). Change in QoL scores was calculated with Wilcoxon Signed Rank Test because the sample was small and all variables were not normally distributed, excepting the item QoL in general. The Spearman's Rank Order Correlation was used to describe relations between variables. Logistic regression analysis was used to identify variables predicting QoL in general.

Content analysis

In studies II and III the intention was to describe the focus group participants' perceptions and not to search for the underlying meaning of the text. Furthermore, the discussions in the focus groups never became as personal as is possible in an individual interview. The participants each had less time to express their opinions and there may be a barrier to expose their inner most feelings and thoughts in front others in the group. In addition to this it was apparent that the participants did not reveal their inner feelings in-depth in focus groups. On the other hand, when the entire text was analyzed the findings gave important information about patients' perceptions on QoL.

According to Krippendorff (2004) content analysis is about unitizing, sampling (not appropriate to qualitative content analysis), coding, reducing, inferring and narrating. The text was divided into meaning units that were sorted to condensed meaning units, which were subsequently coded. The codes, considerations taken regarding the whole text, meaning units and condensed meaning units, were abstracted as close to the text as possible into preliminary sub-themes and finally into themes that narrated the original text. The sub-themes and themes were repeatedly redefined and modified. Themes were created because the text could not be divided into categories that were mutually exclusive and exhaustive but the level of abstraction was not interpretative. By using themes in this way the text could be described more expressively. This level of abstraction can be referred to as having a manifest way of analyzing the content in a text (Krippendorff 2004, Graneheim & Lundman 2004).

In study IV the intention was to acquire an in-depth understanding by interpretation in narrative interviews that manifest content analysis may not provide (Baxter 1991). Interpretations are more complex than descriptive content analysis and the intention is to go beyond the descriptive data (Patton 2002). In this thesis thematic analysis was used. Interpretation was

based on a holistic analysis where the main threads of the meaning of the phenomena were reflected in the themes (Baxter 1991).

The analyzing procedure was performed step by step as in studies II and III, except that in the interpretation the text was read “between the lines” and an underlying message, reflecting the meanings of the phenomenon, was sought. According to Graneheim and Lundman (2004) this level of abstraction can be referred to as having a latent way of analyzing the text. An independent coding process was performed in studies II, III and IV in the research group and themes were discussed and compared, which gave a deeper understanding of the text. An independent coder outside the research group also read the content formed in the classifying process of the analysis in study IV to check the reliability of the sub-themes and themes. This resulted in rewarding discussions between me and the independent coder and sub-themes and themes were further developed.

Ethical considerations

Patients with incurable cancer at the end of life are often very weak and extremely tired so accomplishing scientific research on this population is a difficult and time-consuming undertaking. Therefore, the most important ethical research principle in palliative care is autonomy. This presupposes that patients have the cognitive ability to give informed consent. Patients living with an incurable cancer are very ill and the disease is progressing from one day to another. Their ability to understand the informed consent and the will to participate must be repeatedly followed up by the researcher. Conducting research on terminally ill cancer patients and their families’ experiences of palliative care demands a great deal of sensitivity and special skills from the researcher. The ambition of this thesis was to achieve a balance between patients’ personal ability to make decisions and my own aspiration to do well and not overload patients. Approval was secured from the Ethical Committee at the Medical Faculty at Umeå University (No. 01-320011113).

FINDINGS

The interpretation of the entire analysis in this thesis showed that patients' QoL was maintained, improved or diminished when living with incurable cancer. Physical, psychological and social dimensions of QoL are represented and are in concordance with Haas (1999b) QoL model. However, the existential dimension was more prominent in this thesis than the spiritual dimension, which is not in concordance with Haas (1999b). The most important findings in the qualitative studies (Paper II-IV) with support of the quantitative study (Paper I) have been the bases for the following presentation of findings.

The grade of performance status and survival time is presented initially. The majority of patients in the quantitative study (I) with AQEL and in the qualitative study with focus groups (II) were up and about more than 50 % of their waking hours, which is grade 2 on the Eastern Cooperative Oncology group Scale of Performance Status, (ECOG PS, ECOG 2006). Median survival time after the second measurement was 3.6 months (I). Thirty three patients (52.3 %) estimated that their QoL in general had improved, 11 (17.1 %) that it was unchanged and 19 (30.1 %) that it had diminished after designation. Patients in focus groups (II) were able to travel by themselves to three meetings at the hospital, by car or bus for about 15 minutes up to one hour one way. Patients' median survival time after the completed focus group meetings was 4 months.

In the qualitative studies in focus groups with family caregivers perception of the terminally ill patient (III) and in narrative interviews with patients (IV) patients functional status was at level 3 on ECOG PS. This means that patients were confined to bed or a chair more than 50 % of their waking hours (ECOG 2006). Patients' median survival time after the last focus group with family caregivers was 36 days (III). All patients except one were lying down during the interviews, and median survival time after the interviews was three months (IV).

Issues that maintain or improve patients' QoL when living with incurable cancer

Alleviation from suffering

Patients in focus groups described that receiving alleviation from physical symptoms was important to their QoL (II). Physical well-being was described as being free from physical symptoms, such as pain in e.g. their back or head. Furthermore, patients described that having adequate pain relief made it easier for them to do what they really wanted to do. If pain broke through patients usually took extra doses of morphine but sometimes this was not enough, and in this case patients used personal strategies to relieve pain. The use of these strategies diverted attention from pain and served as pain relief. Patients could distract pain by e.g. keeping her-himself occupied with different tasks in or outside the home, being important to others, and providing pleasure to other people. These findings were strengthened by the results in the quantitative paper, where patients reports (after designation to the PHT) pain correlated significantly ($p=0.350$) with their QoL in general, and was a strong predictor of QoL in general ($p=.028$) (I). Patients also described that it was important for optimal QoL to be free from other physical symptoms, such as dyspnoea, which contributed to an increased feeling of fatigue. Furthermore, being able to sleep, preferably several hours every night, was important for QoL. Also maintaining a good appetite, with the help of pharmaceutical treatment such as cortisone was important (II). In addition patients reported that nausea improved ($p=0.008$) after being designated to the PHT (I).

Patients described that they appreciated normal things and felt functional (II). In spite of the circumstances they were able to perform various daily activities such as doing housework or taking a ride in the car with family and friends. Being free from pain and fatigue as well as retaining balanced rest and physical activities made them feel functional. Furthermore, it was important for patients to retain enough physical strength to enable them to work in the garden or perform other spare- time occupations independently, and to live their lives more or less in the way they had done before they became ill (II). In spite of these findings the results in paper I showed that physical strength and QoL in general had median scores below 6 before and after designation. Regardless of the fact that physical strength scored as low as 3, patients' recumbent hours during the day improved after being designated to the PHT. In addition family caregivers stated that if patients were able to live as normally as possible and felt that they still participated in daily life, this affected their QoL positively. Despite becoming more

confined to bed patients strived to keep up a normal life, or at least kept trying to perform such normal daily activities as watching TV, reading newspapers and books (III).

Psychological well-being was important for alleviation of patients' suffering (II) and this meant not only being free from physical pain but also being relieved from anxiety and depression. This was considered to be as equally important as gaining physical pain relief. Patients reported that anxiety significantly increased ($P=0.007$) and memory significantly decreased ($P=0.33$) after being assigned the PHT (I). Furthermore, depression/feeling low ($r=.55$) had the strongest correlations with QoL in general, i.e. positive or negative changes in a state of depression/feeling low affects QoL in general. Psychological suffering was relieved with the aid of pharmaceutical treatment for anxiety and depression (II). It helped them from crying, to escape despair and increased their will to live. Patients described that it felt good to be free from psychological suffering (such as unhappiness) and that it was positive to be able to experience psychological QoL while still alive.

Obtaining breathing spaces in suffering

Patients approaching death narrated that being relieved from complications provided breathing spaces in their suffering (IV). During this phase patients' QoL clearly improved. Patients also described that receiving effective pain relief and information from the PHT about how to control breakthrough pain enhanced the feeling of independency and security. They regained hope when they received effective symptom control and were free from physical pain, insomnia or loss of appetite. This contributed to an inner peace that enhanced life with a good quality and a feeling of optimism. As well as increasing patients' will to live even if they still lived in an insecure existence. They could appreciate their present life and the feeling of living well also contributed to a sense of hope and being hopeful. Feeling hopeful aroused thoughts that maybe a miracle would take place. This was something outside their control, becoming healthy again or at least hindering the illness from progressing even more. Still being alive, despite having a progressive cancer illness and enduring many phases of complications and personal closeness to death provided them with a sense of victory. Furthermore, patients explained that to be able to prepare themselves and the family for the forthcoming death they required a breathing space in their suffering, i.e. they needed a respite from distress. Being prepared involved airing awkward questions and discussing distressing issues, such as funeral arrangements with the family. Patients also described that being prepared

meant being aware of the complexity of leaving their families, and for the feelings of the family that were being left behind.

Having significant relations

The importance of having significant relations and networks was discussed in the focus group with patients (II). Essential networks were the family, friends, healthcare professionals and the religious network. Being provided with adequate support and help when ill at the end of life was important, family, nurses and physicians in the PHT were extremely important to patients. Support meant that family and the PHT enlightened them from different strains in life and a resonance in communication was developed. This meant that a mutual understanding had developed, which continued during the progression of the disease. It was also essential to have daily contact with relatives for emotional support and to have a spouse with whom patients could talk to about their illness and other problems (II). On the other hand, in the quantitative paper patients reported that social issues such as being accepted as usual by family and friends, and sharing worries with family and friends did not significantly improve after being designated to the PHT (I).

However, patients' described their feeling of security when they knew the PHT was easily accessible (II and IV). The PHT could make home visits even if patients lived several miles from the town hospital. The team also provided a sense of security as patients and their families knew who they could turn to when they needed information or answers to different questions. Recognising the voices and faces of nurses and physicians in the PHT also provided a great sense of security. In addition, family caregivers described that it was important to the patients to be relieved from burdens by receiving support from both family and the PHT (III). These findings are strengthened by the results in paper I as patients reported that after being designated to the PHT getting hold of staff significantly improved ($p=0.000$). To a higher degree they received the care they regarded as appropriate ($p=0.003$).

Being at home

Family caregivers and patients' descriptions showed that being cared for at home was important for QoL (III and IV). Being with the family and spending the last time at home increased the feeling of being a part of a normal and social life (III). It was significant to the ill person to be remembered by friends and to feel needed by family. Patients needed

unconditional support from family caregivers, who were constantly present as they lived on “stand by”, being available both day and night. Family caregivers showed that they acted as a helpful tool to the ill persons providing love, protection, and support. It was also significant for patients to be relieved from burdens and to receive qualified support from nurses and physicians in the PHT. Further, healthcare professionals supported patients’ will to die at home. QoL was maintained as the terminally ill person could lie in their own bed in their own home, which meant everything to them. Patients narrated that being cared for at home gave them a feeling of being independent and secure (IV). For example patients had their family at hand to help them with whatever and whenever they needed help, and they could decide when to receive visits or not. This “feeling of home” provided a sense of security because they could look upon, touch and smell their personal belongings, which made it easier for them to be autonomous and this improved their QoL.

Maintaining a positive life

Patients described that meaningfulness was about maintaining a positive life (II). This included the importance of keeping positive memories alive from the time they were healthy, to provide happy memories now when they were ill. Patients described that good memories reflected the life they had lived, free from incurable illness, and could serve as a source of inspiration to them to maintain as positive life as possible. Meaningfulness also involved the feeling of being needed, which meant that family and friends still counted on them and needed their advice or support concerning family matters. They were seen by others as the human being they were and not only as an ill person. The feeling of being needed strengthened patients’ self-esteem. This was meaningful as it helped patients to find motivation to carry on living and focus on what was happening in the world around them. Family caregivers described that if the terminally ill person had a sense of belonging it was meaningful to them (III). The sense of belonging meant being close to their family, and sharing the aspects of their illness with spouses’ strengthened relations and facilitated intimate moments. Further, being part of a social life and socially involved with others was of the utmost importance to patients. In order to be able to experience a sense of connection it was essential to receive emotional and practical support from relatives and the PHT. It was also meaningful and important for patients’ sense of belonging to pass on inheritance to family members while still alive. The findings about meaningfulness in paper III was supported by the results regarding meaningfulness that scored 5 both before and after designation (I). Meaningfulness also had the strongest correlations ($r=.70$) of all variables in the entire AQEL with QoL in general

after designation, and meaningfulness also ($p = .028$) predicted QoL in general.

Having a sense of dignity

In addition family caregivers described that retaining a feeling of dignity was important for patients' QoL (III). QoL primarily dealt with the fact that the ill family members were regarded as an individual with subjective values, despite suffering from an incurable illness. Patients wanted to continue being a part in decision making and to be respected for the decisions they made. Dignity also meant being treated by others as a human being in the first place and not as an incurable ill person, as well as being met with respect and not being hurt or humiliated by others. Patients wanted to be treated as a whole person and not only as a person with incurable illness. QoL was about being able to bear illness with dignity and preserve autonomy.

Managing life when ill

Patients described in focus groups that it was important to have positive coping strategies that helped them to find motivation in life and to manage life in the best possible way despite being ill (II). Positive coping strategies were described as patients being in charge of the situation, trying to find motivation within oneself, not giving up, and taking control over ones' life by handling difficult situations. This was strengthened further if patients tried not to worry, lived here and now, and continued planning their life and future. Patients also adjusted to the progression of the illness by rearranging their lives and tried to come to terms with the fact that they could not live their lives as before. Despite this being in charge of the situation helped patients to live as optimally as possible. There was a need to reflect on their current QoL. Patients reasoned with themselves about the importance of living life as fully as possible and making the most of every day. Material things did not matter; what mattered was to make the best of the present situation and think positive thoughts. Patients believed that they actually sometimes had a better QoL now, despite incurable cancer than when they were healthy. Managing life when ill was important for patients' QoL because it gave them a sense of independency, and helped them cope with the situation despite having incurable cancer.

Patients stated that it was essential for them to achieve closure of their life while still alive and they could achieve this by passing on an inheritance (II). In this way they contributed to their families' future knowing they

would be remembered after their death. In addition family caregivers described the importance for patients' QoL of being prepared for the forthcoming death. Being prepared was a way to achieve closure of their life and was a part of saying goodbye to relatives (III).

Issues that diminish patients' QoL when approaching death

Being a symbol of incurable cancer

Family caregivers described that the ill person oscillated between being alive and being close to death as she/he became more and more inactive (III). They lost their ability to perform physically, and "didn't fill their calendar" i.e. they did not make plans or were not as busy as they had been before their illness. Furthermore, family caregivers described that being a symbol of incurable cancer was not meaningful. The ill family members became emotionally concerned when the illness could no longer be held secret. When the cancer disease progressed and became visible to other healthy people the patients felt that they had become a symbol of an incurable disease, which impeded their sense of belonging. Progressive incurable cancer will eventually become visible to others as certain medical treatments causes bruising of the skin, or using pain relief in the form of patches, or becoming extremely thin. Not being able to conceal an illness may result in patients feeling stigmatized and this can arouse feelings of being repulsive.

Experiencing intense suffering

Patients explained that they lived in a distressed body (IV), i.e. during the progression of the illness patients experienced phases of intense suffering when acute complications occurred or general health deteriorated, which clearly led to a diminished QoL. Being exposed to unexpected physical symptoms such as e.g. abdominal fistulas, additional dyspnoea at night or intensified pain was described as living in a distressed body. They described that they lived with a death sentence that controlled their entire life. Existence became insecure because they did not know when death would occur. They struggled between life and death as they were determined to live and at the same time they knew that life was ending. They were kept prisoner in their own body as the physical weakness of the body forced them to stay in bed. This contributed to the fact that the patients could not participate in a social life and their will to live declined.

They felt that they could no longer trust their body and that they were controlled by this weakness.

Patients also narrated that when they were in a phase of intense suffering they felt isolated from family and social life. They were cut off from the outside world because they were marked by the state caused by the progression of the illness. Physical closeness was not possible with family members as they were not as mobile as before, which contributed to a sense of not being loved and feelings of loneliness. This was emotionally difficult to handle and curbed togetherness. Being unintentionally isolated from family also produced a feeling of not being a part of the family's future plans. Therefore future goals no longer existed. Patients felt the presence of death and they understood that the illness had entered a new phase, which contributed to a feeling of being even more physically and mentally imprisoned. The patients were also afraid of becoming a burden to the family and health care professionals, and even of being unloved. They felt transformed by the illness both physically and mentally, which gave them a feeling of being an outsider.

DISCUSSION

The overall aim in this thesis was to explore how quality of life (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). An overall description of the main findings is presented in this section. This is followed by a discussion about Haas' (1999b) QoL model, and to conclude, experiences of the QoL and the state of transition when living with incurable cancer, as well as QoL and transition during the last weeks of life are discussed.

The main findings showed that patients approaching death go through a phase that is transitional by nature. Thoughts in association with this are that some incurably ill patients with cancer do not regard their QoL as being as negative as one might expect. However, the time approaching death was not a calm transitory phase during which patients, family and healthcare professionals had time to adjust. Patients' QoL seemed rather to oscillate between intense suffering and acquiring breathing spaces in suffering during the last weeks before death. This is strengthened by paper IV in particular, which provided abundant information on different aspects related to the concept of QoL, and to the issues that led to a potentially improved or diminished QoL. The quantitative study (I) showed that medical care and QoL in general could actually improve after patients had been designated to a PHT, despite their progressive disease. Further, the social dimension of QoL was more obvious in the qualitative paper (II-IV) and not at all in the quantitative study (I). The existential dimension on the other hand was more evident in papers I and III than in papers II and IV. In addition, the physical and psychological dimensions were more or less evident in all of the papers.

Some of the positive factors that have been identified for potentially improving QoL at the late stage of the disease are receiving optimal support by family caregivers and optimal symptom control, being able to stay at home, maintaining as normal an everyday life as possible and being regarded as an autonomous individual. These are also issues that require future staff attention in our striving to help incurably ill patients with cancer to optimize their QoL at the end of life.

A QoL model by Haas (1999a, 1999b) was used as a guide in the literature review to obtain a coherent view of the physical, psychological, social and spiritual dimensions of QoL. The model has certain advantages as it divides QoL into adequate dimensions, which are influenced by subjective and objective indicators. However, the findings are not applicable in its

whole in the model that has to be further developed, and some modifications are needed before application in a palliative care context. The spiritual dimension ought to be extended to include existential issues. Existence should be acknowledged as being a broader term than spirituality and therefore spirituality ought to be integrated in an existential dimension. Furthermore, patients' coping strategies are not included in this QoL model, which is rather surprising as coping strategies are important for maintaining and improving QoL. Haas also emphasized that well-being and satisfaction are not synonyms to QoL but rather indicators of QoL. I agree, QoL is influenced by many factors and in broader terms than well-being and satisfaction. Furthermore, I agree that when assessing patients' QoL an evaluation should be conducted of all four dimensions, before conclusions are made about patients' QoL. As the findings in this thesis indicate, there is no equal balance between the four dimensions. That is, one dimension may influence QoL at one point and at other times another dimension may influence QoL more. This of course is true because the balance between the dimensions may change during the progression of the illness.

Discussion of findings

QoL and transition when living with incurable cancer

Living with progressive cancer at the end of life must be one of the most difficult transitions for patients to face. In this thesis the findings showed that patients mainly experienced quite a positive QoL for the most part. However, during the last weeks of life they oscillated between a state of intense suffering and finding a breathing space in their suffering, which influenced their QoL negatively. According to Kubler-Ross stage theory (1969) dying is a process of emotional stages that patients facing death go through as they progress from a state of denial to acceptance. The author also suggests that other feelings such as anger, bargaining and depression may be experienced during this process. Wilson and Fletcher (2002) however state that other emotions may be prevalent that are not included in the Kubler-Ross model, such as e.g. fear, joy, and hope. Kubler-Ross's findings about the dying process are not in line with the findings in the present thesis. Patients approaching death rather were in a state in which body and mind interacted with each other. Ogden (2000) states that the interaction between body and mind are central in attempts to understand patients' experience of living with a life-threatening illness. This means that body and mind are not separated from each other. Rather they interact in such a way that physical change, e.g. related to bodily organs and the

skeleton, influence a person's feelings and thoughts, i.e. their state of mind. This interaction was also illuminated in the present thesis.

Physical health concerned that patients were *alleviated from suffering* and free from several physical symptoms. Patients described e.g. that they were free of pain. This may well be due to the fact that when patients are designated to a PHT they receive adequate drugs and dosages. They are treated by fewer physicians and their care is supervised by the same nurse. Pain is a prevalent symptom among patients with terminal cancer (Morita, Tsunoda, Inoue & Chihara 1999, Weiss *et al.* 2001, Potter *et al.* 2003, Solano *et al.* 2006), and often overshadows other symptoms (Osse *et al.* 2002). To maintain or protect their physical health the findings in this thesis showed that patients used non-pharmaceutical strategies to distract pain if breakthrough pain occurred. This has not previously been very well described regarding patients with incurable cancer. To have a physical strength to perform daily activities was also important for patients' physical health and QoL. Being able to live as normally as possible was influenced by care being provided at home. Patients strived for a balance between activity and rest, and tried to keep up a normal life as long as they could. Surprisingly, physical strength diminished after designation to the PHT, and at the same time patients became more active. This may be due to the fact that pain was better kept under control through adjustments in the ordinations of analgesics, or that patients were provided with various means of assistance that helped them become more mobile and active. The progression of the disease meant that they consequently lost their ability to perform physical activities, as they grew physically weaker and became more tired. Fatigue affects physical strength and QoL more negatively in patients with cancer than it does a healthy population (Sahlberg Blom, Ternstedt & Johansson 2001). This is in line with the findings in this thesis that elucidated that the weakness and tiredness of the body that patients experienced has to be endured and therefore in their struggle for normality they had to fight more to maintain as normal life as possible.

Being alleviated from suffering was not only about being free from physical distress, but it also involved being free from psychological distress. Body and mind as described above interact in such a way that any change in physical matters influences a person's psychological health. In this thesis patients' psychological health improved as depression was better after being designated to the PHT. This may be due to the fact that patients felt more secure after designation. Further, it may be due to that patients who needed antidepressants were treated with them as well as that pain was better controlled. It is known that unrelieved physical symptoms such as e.g. cancer pain, may cause depression and consequently affect QoL in

general (Mystikadou *et al.* 2005). King *et al.* (2005) emphasized that many patients with depression go undetected and untreated. Block (2006) stated that depression is a treatable condition in patients with terminal cancer. However, a condition for successful treatment is that patients' physical symptoms are controlled. According to Mystikadou *et al.* (2006) patients' psychological well-being is influenced negatively if they experience physical distress. Findings in the present thesis also showed, surprisingly enough, that patients' memory diminished after being assigned the PHT. This is more difficult to explain. It may have been caused by analgesics but an earlier study by Wood Ashby, Somogyi and Fleming (1998) showed that memory is not always influenced negatively by analgesics such as morphine. A more likely explanation is that patients are more cognitively impaired than healthcare professionals perceive in everyday clinical observations.

It was important to patients' social well-being to *have significant relations* as the family and the PHT according to the findings in this thesis. Further, a resonance in communication was developed. That is to say a deeper relation was developed with significant others which provided a feeling of contentment, and are vital for QoL according to Parse (2001). However, progression of the disease may also create feelings of distress and nervous tension on relations (Block 2006, McLean & Jones 2007). On the other hand, talking to others about traumatic events is important for patients' psychological well-being (Mallinger, Griggs, & Schields 2006). In this thesis it was found that significant others also included healthcare professionals in the PHT. They were also important to patients' social well-being. Being able to get hold of staff and receive the necessary care was something that improved significantly after being designated the PHT. This may be explained by that patients had frequent contact with the PHT and always received a speedy response to their different needs (Peters & Sellick 2006). However, Krishnasamy (1996) made a consideration of literature and emphasized that social support sometimes fails to protect patients from the stress of the illness, and provides a supplementary source of distress instead.

The findings *being at home* and receiving care at home was important to patients' social well-being and improved QoL. At home they recognized smells, tastes and touch that aroused positive feelings and reminded them of their lives when they were healthy. They wished to spend their last weeks of life at home were they could conclude their lives. The "feeling of home" gave the patients a sense of being autonomous in an environment that preserved their whole life story. This is in line with Rasmussen, *et al.* (2000) who showed that the consequences of hospice nursing care and the

milieu without hospital care routines was important. The hospice milieu described by Rasmussen, *et al.* (2000) is of course not comparable with a home environment. However, patients at home may find a certain state of health in spite of living with a serious illness (Öhman, Söderberg & Lundman 2003). Being cared for at home in the present thesis meant that patients' QoL was maintained as they could lie in their own bed in their own home that meant everything to them. Spending the last weeks of life at home also increased the feeling of being a part of a normal and social life. Further, at home the family caregivers became a useful tool for the ill person, providing love, protection and support. That is in line with Milberg and Strang (2003) that showed that family caregivers strove to exceed towards something out side themselves in their efforts to provide the best comfort to the ill family member. However, another study showed that family caregivers sometimes feel that they are more or less forced to care for the ill person at home (Wennman-Larsen & Tishelman 2002).

Findings in this thesis elucidated that existential issues as create meaning in life was important to patients possibility to *maintain a positive life* and *having a sense of dignity*. On the other hand, talking about what is meaningful in life was difficult to patients according to findings in this thesis (c.f. Griffiths *et al.* 2002). Difficulties to patients in discussing meaningfulness could be due to the fact that they had not previously reflected on meaningfulness, or it was just too complex to talk about when suffering from incurable cancer. However, it was easier for family caregivers' to talk about and describe meaningfulness. They described that to create meaning in life patients' must have a sense of belonging. This was an interesting finding as meaningfulness generally includes accepting death or enduring suffering (Stewart *et al.* 1999). However, findings in this thesis also elucidated that *being a symbol of incurable cancer* can diminish patients' QoL, and, according to family caregivers, this was difficult for patients. The fact that the cancer illness became visible to others restricted patients' sense of belonging, which led to a feeling of being stigmatized. Being stigmatized by a cancer illness can become a deterrent when trying to find a meaning in life when suffering from a terminal illness. According to Öhman *et al.* (2003) feeling stigmatized also may provide a sense of loneliness. Being a symbol of incurable illness as findings showed in this thesis must have influenced patients' sense of dignity. Family caregivers described how difficult it was for them and the ill person to experience how other healthy people acted disrespectful towards the ill person. Respect in this sense was also described by Bolmsjö (2000) and is closely related to the concept dignity (Chochinov *et al.* 2002). Surprisingly, it was found in this thesis that the patients did not talk about other existential issues as losses of e.g. functions, relations, independency and the future which is

common in the literature (Strang 2002, Murata *et al.* 2006). My experience is that patients were very optimistic during the interviews. Instead of focusing on losses they rather focused on what they could still manage to accomplish in everyday living and not on their shortcomings.

In this thesis findings illuminated that if patients were able to *manage life when ill* they could maintain a better QoL. Having positive coping strategies was a psychological strength influenced by the patient personally and presupposed a good QoL. Positive coping strategies helped the patients to live as optimally as possible, thinking positive thoughts, being reflective, not giving up, living here and now, and continuing to plan for a life and future. That is to say being in charge of their resources (Berterö, Eriksson & Ek 1997). Having positive coping strategies is also described by Vos and de Haes (2007) as distractive strategies that reduces distress. On the other hand, if patients have a poor psychological function it may lead to passive escape-strategies. Coyle (2006) stated that patients struggle to maintain control when facing death. This struggle was not apparent in the findings in this thesis. Patients rather seemed to have a positive outlook and sometimes actually experienced a better QoL at the present time while suffering from incurable cancer than when they were healthy.

QoL and transition during the last weeks of life

The findings in this thesis illuminated that during the last weeks in life patients seemed to oscillate between *being in intense suffering* and *finding breathing spaces in their suffering*. During a state of intense suffering the patients experienced their body as being a distressed “object”, invaded by physical complications that they could not control. They felt as a prisoner in their body that they could not trust as it was too weak. This is in line with Toombs (1993) who stated that people with chronic illness objectify the body or transforms it into a new unit the “diseased body”, because they do not believe that there is a return to normal functioning. The objectification of the body is also described in other studies. Wilson and Fletcher (2002) described this as ‘a stranger-in-the-body’ phenomenon and a feeling of being detached from the body, and the body becomes an hindrance in patients everyday life if it is too weak (Öhman *et al.* 2003). This way of objectifying a body in weakening may be a turning point in the dying process, and a clinical indication that the disease is taking a new direction (Jakobsson *et al.* 2006).

A prerequisite for the finding in this thesis regarding acquiring breathing spaces was that patients were free from acute complications or that they felt an improvement in their general health. Breathing spaces in suffering gave

patients an opportunity to regain hope and helped them to appreciate their present life. The findings in present thesis that related to hope and feelings of an inner peace may be a consequence of the body being given a chance to acquire a respite; consequently the mind was able to concentrate on the present situation. This is in line with Rehnsfeldt and Erikssons (2004) who showed that being alleviated from suffering acquired that patients became conscious about that they are suffering. Another finding in this thesis, in relation to acquiring breathing spaces in suffering, was the necessity for patients to prepare for death, not only by preparing themselves but also their family. There is hardly any previous research on preparedness, but Hebert Prigerson, Schultz and Arnold (2006) emphasize that family caregivers are not as ready for the death of their ill family member as one may think. Therefore, healthcare professionals in palliative care must have an open communication about death and dying, which will enable families to become better prepared.

This thesis did not show the last weeks of life as being a calm, transitory phase during which patients, family and healthcare professionals had time to adjust. It was described instead as a time of heavy swells coming and going, during which patients never knew what ordeal would appear around the next bend. This kind of oscillation is described in previous literature by Qvarnström (1979) as fluctuation between extremes. Further, Öhman *et al.* (2003) illuminated this as drifting between suffering and enduring suffering and Lindqvist *et al* (2006) described it as alterations in cyclic movements. James, Andershed and Ternstedt (2007) showed that the entire family's beliefs about cancer, dying and death move back and forth, influencing daily life. In this thesis findings illuminated that when living in transition the last weeks of life the body and mind did not seem to interact at all but seemed indeed to be more segregated. That is, patients lived in a deteriorating body restricting them in performing daily activities, and at the same time they were mentally active and engaged in life. The meaning of the living body and its interaction with the mind when approaching death is not commonly discussed among nurses in palliative care. Rather when the body is in focus it is about caring for the ill patients and handling the newly dead.

During the writing of this thesis I realized how complex QoL really is and that living with progressive cancer illness must be one of the most difficult transitions for patients to face. However, it also illustrates that it is feasible to perform research in patients near the end of life and maintain rather complete data. The findings may be useful to healthcare professionals who care for patients at the end of life regardless of setting and hopefully

providing a deeper understanding of those patients and their families' who have a need to talk and share experiences of QoL when facing death.

METHODOLOGICAL CONSIDERATIONS

In this thesis both quantitative (I) and qualitative (II-IV) methods were used to express the phenomenon QoL. A mixed design was considered as the most suitable method for exploring such a complex phenomenon and this imparted a number of perceptions regarding QoL. In paper I the study provided a quantity of information on what factors influenced and changed patients QoL. The depth of the conversations in the qualitative studies differed, depending on context, but then it is probable that most participants in the focus groups did not reveal their innermost thoughts as comfortably as in individual interviews. Focus group interviews with patients were conducted first. The purpose of this was to create a first database with information regarding patients' perceptions of QoL, which encompassed and outlined the phenomenon. Following this additional information was acquired from papers II-IV. Each paper in this thesis comprises a complete investigation, but when the text and numeric information were compared and integrated with each other in the interpretation of the entire analysis a deeper understanding of QoL was achieved.

Sample

There are several practical and ethical difficulties to be overcome when recruiting participants to research studies in palliative end of life care. Recruiting and obtaining sufficient patient numbers are particularly difficult due to gate keeping (i.e. unwillingness by responsible staff to enroll their own patients in research studies) by ethical committees, professional control, patient and family gate-keeping (Hudson, Aranda, Kristjanson & Quinn 2005). Other obstacles may be small sample sizes, high attrition rates, rapidly changing clinical situations and limited survival time (Hudson, Aranda & McMurray 2001, Grande & Todd 2000).

Paper I

One of the restrictions in internal validity (Polit & Beck 2004) to consider in this study was the fact that the patients were very ill and that the illness could progress rapidly. The severity of the disease forced 100 of 163 participants to withdraw their participation before the study was completed. Consequently, due to the fact that the most critically ill patients did not participate we can assume that the findings are more positive than they would have been if the whole cohort had been included. External factors

could have affected the results in either direction, e.g. if patients or their family experienced positive or negative occurrences during data accumulation. Furthermore, palliative treatment may have changed patients' symptom experiences. The fact alone that patients were very close to death may have affected the results.

A consecutive sampling procedure was used because it was considered as being the most practical and ethical way to recruit patients to the study. At first, when designing the study, the intention was to use a random sampling design. This design was later abandoned because of the ethical problem of randomizing patients at the end of life to a control group, in this case implying that they should be designated to the PHT with a delay of at least a period of two weeks. That is to say, not being provided with the PHT care they wished for and which was indeed necessary for medical and psychosocial reasons.

When using quantitative measures of QoL within palliative care the characteristics of a questionnaire such as the AQEL are invaluable. It is easy to complete, resulting in very little missing data. It is also suitable for use when assistance is needed for completion, i.e. someone reads the questions to a patient too weak to fill in the questionnaire independently, and the patient answers with the appropriate number 1 to 10. The answering format also makes it sensitive to change even on the declining slope of a progressive disease. After certain modification it could well serve as a complement to clinical assessment and decision-making as well as support in communicating problems between patients, healthcare professionals and family. AQEL has previously been used in patients with lung cancer at a clinic for treating breathlessness (Hatley *et al.* 2003) and in patients with lung cancer in palliative care with focus on dyspnoea (Hench, *et al.* 2007).

Paper II-IV

The purpose of using focus groups (II and III) was to form groups of participants with similar experiences of incurable cancer, which would provide a focused exploration of the QoL concept. However, this did not mean that collected data did not provide variations in the descriptions of participants' perceptions. Rather that participants had a common platform from which they could exchange different experiences relating to QoL. For the individual interviews with patients (IV) it was essential to recruit patients who had the motivation and ability to verbalize their experiences.

However, non-participants with less symptom control and a poorer general condition were more inclined to withdraw from participation in the study.

Collecting data using qualitative methods was particularly successful for achieving a deeper understanding of QoL. I used myself as an instrument and became involved in the patients and family caregivers' positive and negative life events. For the most part the conversations were calm, the participants relayed a kind of optimism and they were willing to share their experiences with me. Using me as an instrument required certain preparations. The interview questions had to be thoroughly considered and discussed in the research group. It was also important to have contact with the patients before the interview in order to confirm that we could still proceed with the interview. During the interviews it was important to be sensitive to patients' and family caregivers' expressions of every word, as well as being aware of their needs for breaks, e.g. drinking water or taking analgesics. I felt privileged in being allowed the opportunity to listen to their experiences and patients and family caregivers seemed to appreciate being listened to.

Trustworthiness

Credibility is the key principle in qualitative research and in papers II-IV efforts were made to afford the themes descriptions that were as vivid and as detailed as possible, in order to communicate the findings as clearly as possible. Each focus group (II and III) met on three occasions which provided a better understanding about patients and family caregivers' opinions on QoL. Repeating focus groups meetings also gave the participants a feeling of security, which provided a platform for communicating details on issues concerning QoL. I also tried to give prominence to the participants' values and withhold my own during the analyzing process.

All four papers have been reviewed in the research group, doctoral seminars, and in paper IV an external researcher examined the trustworthiness in sub-themes and themes. My different experiences as a registered nurse, both in the county council surgical care as well as in community health care services, meant that I had a certain pre-understanding about patients with incurable cancer. Possessing different clinical experiences could be a weakness if the meaning of these pre-conceptions is not clear. Therefore it was essential to have continuous discussions with the co-authors in the papers included in this thesis,

clarifying the best way to investigate and analyze QoL in patients with incurable cancer.

A limitation in the present thesis was that the studies only took place in a single health care setting. Less than half of the approached patients accepted participation in all of the studies. As those with more prominent symptoms and a poorer general condition are more likely to be among the non-participants this may bias some aspects of the views presented on QoL. In paper IV the majority of participants were men. However, during the analysis of the data in paper IV no gender differences were distinctly apparent. The use of both descriptive and interpretive content analysis, as well as statistical analysis that illustrated different aspects of the concept of QoL in end of life home care must be considered as a strength. Content analysis was used both comprehensively and in-depth. That is to say, the levels of abstraction varied and created themes that described both circumstances and deep emotions, depending on data collection methods and the content of the text. The findings in this thesis cannot be generalized but are transferable and applicable to patients with incurable cancer and also to other patients with incurable illness in palliative homecare.

CONCLUSIONS

This thesis has added to our understanding and knowledge of QoL for patients living with incurable cancer, while being cared for at home with support from family caregivers and a PHT. The QoL model (Haas 1999b) that was used as a guide in this thesis was useful for sorting the findings from the different studies. Even if existential issues and coping strategies was difficult to apply in the model. The empirical findings in this thesis are a theoretical contribution in the way that QoL in palliative homecare has been given a multidimensional content. Major findings illustrated how complex QoL in fact is and that the last weeks of life was not a calm transitory phase during which patients, family and professionals had time to adjust emotionally. Body and mind became more segregated than at any other time during the transition phase. In spite of this it was essential to patients QoL to be a part of a daily and social life. Findings also illustrated that some patients with incurable cancer did not regard their QoL as being as negative as one might expect.

CLINICAL IMPLICATIONS

The findings in this thesis can be useful for healthcare professionals to implement in palliative care. With increased knowledge and understanding care can be improved by focusing on positive aspects of QoL, e.g. by encouraging patients to verbalize positive aspects in their individual lives. One way is to empower the patients to talk about what they enjoyed in life in the past and what they enjoy in life at the present, and inquire about matters in life that can improve QoL. Healthcare professionals in end of life care can also encourage patients to participate in social life as much as they can before the disease progresses and the patients become more confined to bed.

It is vital that nurses and physicians in palliative clinical end of life practice understand that the pattern of QoL is individual and that they have to adjust care to the present phase of each individual. When patients have a breathing space in suffering healthcare professionals have a unique opportunity to support patients and families psychologically, socially and existentially thus promoting the best possible QoL.

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. End of life care should, as much as possible, practice intensive symptom alleviation and devise opportunities to enable patients to stay at home as long as they wish, and care should be adjusted to the current phase of each individual. The findings, excepting palliative homecare, may also be applicable on hospital wards if healthcare professionals receive the proper training and can be given the time that is required when caring for patients at the end of life. Palliative care must be better integrated in the medical oriented care culture as hospitals as well as in nursing oriented care culture as e.g. nursing homes.

FURTHER RESEARCH

Little is described in research literature about how to implement the knowledge on QoL at the end of life in clinical practice, i.e. knowledge that is clinically applicable to nurses and physicians in palliative care, who are occupied with the task of optimizing the QoL of incurably ill patients facing impending death. In a future project it would be of interest to investigate how healthcare professionals in palliative care can meet patients' different existential needs. There is a need in research to make an intervention to study if existential conversations between healthcare professionals and patients could relieve symptoms and maintain/improve the QoL of patients with incurable cancer in palliative care.

SVENSK SAMMANFATTNING

Patienters livskvalitet – Leva med obotlig cancer i palliativ hemsjukvård.

Bakgrund

Fokus för avhandlingen har varit patienters livskvalitet vid obotlig cancer som vårdas hemma med stöd av familj och ett palliativt hemsjukvårdsteam. Intresset för detta var att jag i det kliniska arbetet upplevt att det dagliga livet blir komplicerat för patienter som lever med obotlig cancer och deras familjer. Trots detta så verkar det som om patienterna i livets slutskede ändå verkar ha en ganska bra livskvalitet. Men att reaktioner på olika symptom och hur de mår är relaterat till hur långt sjukdomen har avancerat. Palliativ vård eller lindrande vård ges till patienter då botande vård inte längre är möjligt. Ett av den palliativa vårdens mål är att ge en så god livskvalitet till patienter och deras familjer som möjligt. Trots detta är lite känt om hur patienter i livets slutskede upplever sin livskvalitet.

Syfte

Det övergripande syftet med avhandlingen var att undersöka vad som påverkar och vad som är av betydelse för livskvaliteten vid obotlig cancer när patienten vårdas i hemmet med stöd av anhörigvårdare och ett palliativt hemsjukvårdsteam.

Metod

Totalt deltog 76 patienter som var mer eller mindre sängliggande samt 4 anhörigvårdare. Kombinerade metoder användes, övervägande intervjuer som analyserades med innehållsanalys. Data som samlades in med frågeformulär analyserades med icke-parametriska test.

Resultat

Patienter som närmar sig döden lever i en period av förändring (transition). Detta innebar inte att patienterna hade en dålig livskvalitet, vilket man kunde förvänta sig. Trots detta så var tiden några veckor före döden inte någon lugn tid då patienterna, deras familjer och vårdpersonal hade tid att anpassa sig. Patienternas livskvalitet verkade snarare pendla mellan lidande och perioder av återhämtning i lidandet.

Perioder med akuta komplikationer gav sämre livskvalitet och ett ökat lidande men perioder av återhämtning i lidandet gav en förbättrad livskvalitet. Under denna period kunde hoppet återfinnas och patienterna kunde vila i att vara lindrade från fysiska symptom.

Efter anslutning till det palliativa hemsjukvårdsteamet behövde patienterna inte vila lika mycket som tidigare och illamående, samt oro och depression förbättrades. Patienterna upplevde för det mesta ett fysiskt välbefinnande och de var smärtfria men om de fick genombrottssmärta använde de sig av personliga icke-medicinska strategier för att distrahera smärtan. De hade ork att utföra dagliga aktiviteter och försökte att leva så normalt som möjligt.

Det var viktigt att ha ett socialt nätverk och att vara nära sin familj och att få vara hemma. Att få bekräftande vård och stöd i hemmet bidrog till att patienterna kunde upprätthålla ett välbefinnande. Patienter beskrev också att det var lättare att komma i kontakt med vårdpersonal, samt att vården förbättrades efter det att de blev anslutna till det palliativa hemsjukvårdsteamet. En ömsesidig förståelse utvecklades mellan patienterna och deras familjer, och mellan patienterna och vårdpersonalen under det att sjukdomen avancerade. Efter anslutning till det palliativa hemsjukvårdsteamet visade det sig att känslan av meningsfullhet relaterade starkt till den övergripande livskvaliteten. Det vill säga låg känsla av meningsfullhet kan minska livskvaliteten och hög känsla av meningsfullhet kan öka livskvaliteten. Livet kunde fortfarande kännas som meningsfullt så länge patienterna upprätthöll en positiv livssyn och hade goda minnen att tänka tillbaka på. Det hjälpte också om andra människor i deras omgivning såg människan bakom sjukdomen, dvs. att patienterna bemöttes som den människa de en gång var och inte bara som en människa med obotlig cancer. Anhörigvårdarna gav termen meningsfullhet ett nytt innehåll och beskrev detta som en känsla av samhörighet. Dessutom beskrev de att när sjukdomen blev synlig för omgivningen var mindre meningsfullt för patienterna eftersom de blev uppfattade av andra som att vara en levande symbol för obotlig cancer. De försökte förbereda också sig själva och familjen inför den kommande döden medan de fortfarande levde.

Diskussion

Att leva med obotlig cancer måste vara en av de svåraste förändringsperioder som patienter går igenom. Resultaten i denna studie visar att leva nära döden är inte enbart en känslomässig process utan snarare ett tillstånd där kropp och själ samverkar med varandra. Ett lindrat lidande för patienterna innebar att vara fri från fysiska och psykiska symptom. De

beskrev t.ex. att de var smärtfria vilket kan bero på att efter anslutning till ett palliativt hemsjukvårdsteam fick de adekvat behandling. Dessutom behandlas de av några få läkare samt att de hade kontinuerlig kontakt med en och samma sjuksköterska i teamet. Patienternas livskvalitet påverkades också positivt av att de hade egna smärtlindringsstrategier, vilket inte är så väl beskrivet tidigare när det gäller patienter med obotlig cancer. Att även det psykiska välbefinnandet ökade efter anslutning till det palliativa teamet kan bero på att patienterna fick adekvat behandling för detta samtidigt som de fysiska symptomen var kontrollerade. Den regelbundna kontakten med vårdpersonalen i teamet, att de snabbt fick sina behov tillgodosedda, samt att de fick vård i hemmet kan också vara bidragande faktorer. Det har visat sig även i andra studier att om fysisk smärta inte är behandlad påverkar det psykiska välbefinnandet. Dessutom visade det sig att patienterna hade en psykisk styrka i och med att de kunde bemästra sitt liv som sjuk med olika positiva strategier som att tänka positiva tankar och att inte ge upp. Trots att patienterna var väldigt positiva var det svårt för dem att tala om existentiella värden såsom meningen i livet. Detta kan bero på att de inte tidigare hade reflekterat över detta eller att det var svårt att tala om sådant som är så personligt. Dessutom blev livet svårare för dem när sjukdomen blev synlig för andra vilket innebar att patienterna kände sig utpekade. De sista veckorna verkade livskvaliteten pendla mellan lidande och perioder av återhämtning i lidandet. Under denna tid av pendling verkade inte kropp och själ vara lika samspelta med varandra som tidigare. Snarare upplevdes kropp och själ som olika enheter som var och en levde sina egna liv. Det var av betydelse för den upplevda livskvaliteten att vid återhämtning i lidandet kunna förbereda sig själv och familjen för döden. Trots detta är inte familjen så förberedd som man skulle kunna tro. Detta kan bero på att de är så upptagna av att vårda den sjuke så de har helt enkelt inte tid att förbereda sig. Därför är det viktigt för vårdpersonal i den palliativa vården att ha en öppen kommunikation om döendet och döden med dem vilket kan möjliggöra att både patienterna och familjen blir bättre förberedda.

Vård i livets slutskede borde så mycket som möjligt praktisera intensiv symptomlindring och möjliggöra att patienterna får stanna hemma så länge som de önskar, och vården ska också anpassas till den aktuella fas i sjukdomen som patienterna befinner sig i. Trots de svårigheter som patienterna med obotlig cancer och deras familjer som medverkade i denna studie gick igenom den sista tiden i livet så var intervjuerna med dem väldigt positiva. De hade ett stort behov av att tala om sin situation och många av patienterna upplevde att de hade en relativt bra livskvalitet.

Sammanfattning

Resultaten visade hur svårt det kan vara att leva med obotlig cancer och hur komplicerad patienters livskvalitet är. De sista veckorna i livet var inte en lugn förändringsfas under vilken patienterna och deras familjer samt vårdpersonal hann anpassa sig till de snabba förändringar i tillståndet som sjukdomen medförde. Kropp och själ var dessutom inte lika förenade med varandra som de varit tidigare under sjukdomstiden. Trots detta var det viktigt för patienterna att vara delaktiga i det dagliga och sociala livet under hela sjukdomstiden. Resultaten visade dessutom att patienter som lever med obotlig cancer har en ganska bra livskvalitet men har behov att tala om sin upplevda livskvalitet med anhöriga och vårdpersonal.

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