

Relatives in end-of-life care – part 1: a systematic review of the literature the five last years, January 1999–February 2004

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Aim. To review systematically research conducted during the past five years focusing on the relatives' situation and needs in end-of-life care.

Background and aim. That relatives make a large contribution in the care of the dying is well-known. In this situation, relatives often have to solve many new practical problems in the care as well as dealing with the sorrow of both themselves and the dying person. In recent years, palliative care has been developed in many countries and many new studies have been carried out.

Methods. A systematic search of the literature was performed in the CINAHL and Medline databases. Of the 94 papers analysed, there were 59 qualitative and 35 quantitative studies with differing designs. The studies were carried out in 11 countries and were published in 34 different journals.

Results. The results were categorized in two main themes with several subthemes: (1) being a close relative – the situation: (i) exposed position – new responsibility, (ii) balance between burden and capacity and (iii) positive values; (2) being a close relative – needs: (i) good patient care, (ii) being present, (iii) knowing and communicating and (iv) support from and trusting relationship with the professional. The relative's feelings of security and trust in the professional were found to be of great importance.

Conclusion. More than twice as many studies had a descriptive/explorative design, which is of importance in the assessment of evidence. However, different studies complement one another and in summary, it can be said that analytic evidence is unequivocal: good patient care, communication, information and the attitude of the professional are of decisive importance regarding relatives' situation. These results are also in accord with earlier review studies.

Relevance to clinical practice. Staff members have a great deal of responsibility for assuring that the patient feels as good as possible, facilitating relatives' involvement based on the family's wishes and limiting the stress and difficulties experienced by the family. The results showed that the relative's satisfaction could depend on the attitude of the professional as well as on good communication, good listening and good information. This can also be viewed as a prerequisite for the professional to get to know the family and to provide 'care in the light'.

Key words: family, hospice, literature review, palliative care, relative, terminal care

Introduction

Being a close relative/next of kin of someone in the final phase of life is often complicated. It can be the relative's first concrete encounter with dying and death. In this situation, the relative must handle both his/her own sorrow and that of the dying person, in addition to solving a multitude of practical problems. All this in a life situation where existential questions come to a head and where it is not certain that the relative, the patient or the professional are prepared to talk about the situation. Living close to the patient and assuming responsibility for assuring that he/she feels as good as possible can be a matter of course for many relatives, while for others this can involve great sacrifices.

Previous studies have shown that relatives need support for their own sake as well as to enable them to be close to and support the patient (Andershed 1999). Regarding the role of care recipient, studies have described relatives' needs, the stress they could encounter and how their own health and quality of life were affected. In the role of caregiver, relatives' involvement, their wish to be with the patient and what they did to make the situation easier have also been described (e.g. Hull 1992, Kristjanson & Ashcroft 1994, Davies *et al.* 1996, Harrington *et al.* 1996, Grande *et al.* 1997, Andershed 1999, Ferrell 1999). In recent years, palliative care has undergone continued development and many new studies have been carried out. The aim of this study was therefore to review systematically research conducted during the past five years focusing on the situation and needs of relatives in palliative care.

Method

Systematic review of the literature

The systematic search of the literature was performed in the CINAHL and Medline databases using the following search words and combinations: palliative care/OR terminal care/OR end-of-life AND family/OR relatives OR spouse OR next of kin, NOT review, NOT child, NOT paediatric care, NOT intensive care. The searches were restricted to studies published in English for the period from January 1999–February 2004. With these limitations, 455 papers were identified in Medline and 205 in Cinahl, and 40 studies were added through unsystematic searches.

Selection

The identification of relevant studies involved different steps. First, the reviewer screened the titles and abstracts obtained

from the search. Based on this review approximately 500 references were excluded as they did not meet the following inclusion criteria: empirical studies in palliative care where adult relatives/next of kin were questioned about their situation and needs. Studies based only on a patient/professional/organization perspective or that described different questions concerning withholding/withdrawing treatment, assisted suicide/euthanasia or developed/tested instruments/questionnaires were also excluded.

In the second step, approximately 200 studies were retrieved in full form as they potentially met the criteria for inclusion. In addition to the above inclusion and exclusion criteria, papers were excluded in this run-through that focused only on grieving after the patient's death. This could be questioned, since support to grieving relatives is included in palliative care. However, it was nevertheless considered a clear delimitation.

In the third step, the methodological quality of the remaining studies (109) was assessed. Studies of medium to high methodological quality were included. In accordance with Polit and Beck (2004), criteria for high quality were that the study was well-planned and well-carried out with well-defined research aims/questions, that it had a relevant and well-described selection of participants/context and an adequate and well-described/conducted method and analysis.

Classification and analysis

Ninety-four studies were included in the review and these were read repeatedly. Thereafter, data from the articles were entered into two matrices, one for qualitative studies and one for quantitative studies. The study designs were classified according to Brink and Wood (1998) into: (i) experimental designs (classical experimental, quasi-experimental and evaluation), (ii) survey designs (comparative and/or correlational) and (iii) exploratory-descriptive designs.

In the next step, the main results of the studies were analysed with respect to the situation and needs of relatives. The results were categorized in two main themes with several subthemes: (1) being a close relative – the situation: (i) exposed position – new responsibility, (ii) balance between burden and capacity and (iii) positive values; (2) being a close relative – needs: (i) good patient care, (ii) being present, (iii) knowing and communicating and (iv) support from and trusting relationship with the professional. The themes/subthemes do not have distinct boundaries, but instead partially overlap one another. Consequently, some statements could be assigned to several themes/subthemes.

Results

Of the 94 papers analysed, there were 59 qualitative and 35 quantitative studies with differing designs (Table 1). Of the studies that were categorized as having experimental designs, three had quasi-experimental and three had evaluative designs. The studies with a survey design mainly used different questionnaires for data collection. The category of descriptive/exploratory studies comprised qualitative studies as well as seven quantitative studies where the data were analysed using only descriptive statistics. The studies were carried out in 11 countries (Table 2) and were published in 34 different journals, the most frequent of which are seen in Table 2.

The studies focused mainly on relatives of cancer patients, but diagnoses such as ALS, AIDS, brain tumour, haematologic malignancy, muscular dystrophy, dementia and stroke were also found. The concept of relatives/family was termed caregiver, carers, informal carers, primary informal caregivers, primary caregivers, home caregivers, cancer caregivers, caring relatives, relatives, surviving/widowed spouses, next of

Table 1 Classification of the studies

Design	Total (<i>n</i> = 94)
Experimental	6
Survey	22
Descriptive/explorative	66

Table 2 Country where the studies were carried out and journals where the studies usually were published

	Qualitative	Quantitative	Total
Country			
Europe*	29	10	39
USA	11	13	24
Australia	9	3	12
Canada	7	4	11
Asia†	3	5	8
Journal			
<i>Journal of Palliative Care</i>	11	4	15
<i>International Journal of Palliative Nursing</i>	10	2	12
<i>Palliative Medicine</i>	3	7	10
<i>Cancer Nursing</i>	3	2	5
<i>Journal of Pain and Symptom Management</i>	2	3	5
<i>Oncology Nursing Forum</i>	1	3	4
<i>Am Journal of Hospice and Palliative Care</i>	2	1	3
<i>Journal of Advanced Nursing</i>	3		3

*UK 19, Sweden 16, Finland 1, Norway 1, Nederland 2.

†Hong Kong 5, Japan 2, Taiwan 1.

kin, family caregiver, family carers, family member and family. Irrespective of the name, the meaning was the same – one person as a voice for the family. The patient was not included in the concept of family, although data concerning the patient were sometimes included in the studies. In the following results, the concept most frequently used is that of relatives.

Being a close relative – the situation

Exposed position – new responsibility

Being a relative at the end-of-life was quite a new situation for many people. A number of studies described how relatives were in an exposed position involving increased vulnerability. Relatives often experienced the situation as burdensome and as involving increased responsibility, which could have negative consequences such as fatigue, anxiety, agony, fear, difficulty sleeping, lack of time, loneliness, a loss of control, difficulty understanding, a feeling of helplessness, uncertainty, conflicts within the family, financial burdens, loss of dreams and/or speculations concerning the future and a new life situation (Enyert & Burman 1999, Jarrett *et al.* 1999, Yates & Stetz 1999, Adelbratt & Strang 2000, Aranda & Hayman-White 2001, Grbich *et al.* 2001, McGrath 2001, Scott 2001, Scott *et al.* 2001, Somerville 2001, Stajduhar 2003, Strang *et al.* 2002, Wennman-Larsen & Tishelman 2002, Brazil *et al.* 2003, Dawson & Kristjanson 2003, Koop & Strang 2003, Loke *et al.* 2003, Proot *et al.* 2003, Hudson 2004, Milberg *et al.* 2004, Oldham & Kristjanson 2004). Payne *et al.* (1999) reported that the majority of relatives experienced an above normal level of psychological distress/strain and Hawkins (2000) found that relatives (87%) experienced greater anxiety than the patient (36%) regarding the patient's anorexia. Schulz *et al.* (2003) showed high level of depressive symptoms while family members of persons with dementia providing care, but they also showed remarkable resilience after the death.

In a study by Weitzner *et al.* (1999), it was also found that ratings for both physical health and quality of life of relatives in palliative care were lower than ratings for relatives in curative care. Borneman *et al.* (2003) studied relatives' quality of life in connection with palliative surgery and found that relatives were anxious about risks related to the operation and care after the operation. The results showed that relatives' quality of life was poorer after than before the operation.

Relatives described the transition in roles involved in becoming a family caregiver and that this could be a time of uncertainty and turbulence (Andershed & Ternstedt 2001, Wennman-Larsen & Tishelman 2002, Brobäck & Berterö

2003). For example, relatives spent many hours checking on symptoms experienced by the patient, such as fatigue, pain, dry mouth, poor appetite, vomiting and constipation and these were experienced as difficult to manage (Aranda & Hayman-White 2001, Newton *et al.* 2002). Sometimes mental symptoms such as depression, confusion and hallucinations were also hard to handle (McRae *et al.* 2000, Newton *et al.* 2002). Another finding was the feeling of helplessness associated with progression of the illness, struggling to obtain the services they needed and the inability to relieve pain and discomfort (Dawson & Kristjanson 2003, Milberg *et al.* 2004, Oldham & Kristjanson 2004, Perreault *et al.* 2004). They sometimes had difficulty reporting the patient's pain and how it was handled and they could withhold information from the professional. Reasons for underreporting included fear of side effects, which they felt could shorten the patient's life and fear that the patient would become addicted (Lin *et al.* 2000, Ogasawara *et al.* 2003). Keefe *et al.* (2003) found that caregivers who rated their self-efficacy in helping cancer patients manage pain as high also reported lower levels of strange moods and an increase in positive moods in themselves. This can be compared with a study where researchers used the metaphor of being 'in pain state' when relatives experienced feelings of fear, helplessness and unfairness. They were unable to alleviate the pain and were forced to seek help. The 'out of pain state' metaphor described the situation when the patient's pain was alleviated and the relative could relax (Mehta & Ezer 2003, *cp.* Oldham & Kristjanson 2004).

Many also experienced difficulties in the caregiving itself, both at home and in the hospital (Newton *et al.* 2002, Stajduhar 2003). For example, relatives had difficulty performing personal hygiene (Rhodes & Shaw 1999). Much was demanded of them, even when they had the support of hospice care. In the study by Newton *et al.* (2002), 64% of the relatives estimated that they provided care 12–24 hours/day (*cp.* e.g. Schulz *et al.* 2003). Brazil *et al.* (2003) also found that during the final three months the burden experienced by relatives and the care they provided had a cumulative effect.

In many studies, those providing care were primarily women (e.g. Emanuel *et al.* 1999), but it was also shown that men were active in the care (e.g. Rhodes & Shaw 1999). Studies also described how it could be more difficult to care for young relatives (Chan & Chang 2000), to be female (Payne *et al.* 1999, Rollison & Carlsson 2002) to be a young caregiver (Payne *et al.* 1999, Chan & Chang 2000, Goldstein *et al.* 2004), to have a lower level of education (Weitzner *et al.* 1999, Scott *et al.* 2001, Cameron *et al.* 2002) or a limited social network (e.g. Powazki & Walsh 1999,

Andershed & Ternstedt 2001, Strang & Strang 2001, Strang & Koop 2003, Goldstein *et al.* 2004). A rapid trajectory (Andershed & Ternstedt 2001) and/or lower sense of coherence (Andershed & Ternstedt 2001, Milberg & Strang 2004) could also increase the difficulties relatives experienced. Stajduhar and Davies (1999) described that the stigmatization associated with AIDS could be an additional burden for relatives.

Balance between burden and capacity

Proot *et al.* (2003) reported that relatives constitute a risk group for increased ill health. The authors developed a model describing the importance of a continuous balance between burden and capacity in order to master the situation. Vulnerability was illustrated on a scale where burden was defined as vulnerability-increasing factors (care burden, restricted activities, fear, insecurity, loneliness, facing death and lack of support) and capacity as vulnerability-decreasing factors (continuing previous activities, hope, keeping control, satisfaction and good support). Relatives' emotional stress could increase if caregiving caused limitations in valued activities/interests, irrespective of care workload (Cameron *et al.* 2002, Goldstein *et al.* 2004). Powazki and Walsh (1999) described how the professional used family conferences on an acute palliative medicine unit to identify families at increased psychosocial risk.

A number of studies also took up different ways of handling the situation, so-called vulnerability-decreasing factors or coping strategies such as relatives' own activities (tai chi, dancing, soccer, going out to eat/shop and walks), having hope, having control, taking one day at a time, satisfaction with the care, good support and good information (Stajduhar & Davies 1999, Yates & Stetz 1999, Grbich *et al.* 2001, Scott *et al.* 2001, Strang & Strang 2001, Proot *et al.* 2003). Strang *et al.* (2002) studied the concept of respite and showed that relatives distinguished between mental and physical pauses. Mental pauses such as reading, listening to music/TV, going into another room, doing needlework and meditating were important. Kristjanson *et al.* (2004) evaluated a service of night respite community palliative care and found that the main reason family members used this service was that they were suffering from exhaustion and caregiver fatigue (*cp.* Rhodes & Shaw 1999).

Relatives' sense of coherence, inner strength and fighting spirit were also found to be of importance in handling the situation (Andershed & Ternstedt 2001, Strang & Strang 2001, Milberg & Strang 2003, Strang & Koop 2003). Some relatives experienced feeling an inner strength that they had not realized they had. The patient's inner strength was also of help to relatives and acted like a strong buffer that absorbed

some of the emotional impact of the caregiving situation (Strang & Koop 2003).

Positive values

Research about relatives in palliative care has tended to focus on problems and negative aspects (Hudson 2004). However, some studies have described relatives' valuable experiences including feelings of satisfaction, thankfulness and pleasure. They could feel that coping with the situation gave meaning to the final time together with the dying person. Thus this time could be of importance to the relatives despite personal hardships. The fact that they felt of value and that they experienced an inner strength as well as other positive feelings could help them handle the situation (Enyert & Burman 1999, Stajduhar & Davies 1999, Andershed & Ternstedt 2001, Grbich *et al.* 2001, Strang & Strang 2001, Koop & Strang 2003, Proot *et al.* 2003, Hudson 2004). They described how they could demonstrate their love for the patient, which was also a way of paying back what they had previously received from their loved one (Stajduhar & Davies 1999, Grbich *et al.* 2001). Stajduhar (2003) described how the experience gave some relatives new ways of learning about both themselves and the patient. The benefits of caring and the sense of loving were evident (Mok *et al.* 2003, Oldham & Kristjanson 2004). Schulz *et al.* (2003) also showed that the death could be a relief for the family (Koop & Strang 2003).

Being a close relative – needs

Good patient care

An important need on the part of relatives was the assurance that the patient got care of high quality that the patient's wishes were respected and that the patient was content (Weitzner *et al.* 1999, Keegan *et al.* 2001, Mok *et al.* 2002, 2003, Milberg *et al.* 2003). Relatives felt supported and experienced peace of mind when they knew that professionals were acting in their dying loved one's best interest. They could also feel that they had fulfilled their duties and responsibilities, 'they had performed what they could' (Mok *et al.* 2002). Steinhauser *et al.* (2000) reported that families feared bad dying more than death and Dunne and Sullivan (2000) found that the most stressful factor experienced by relatives was poor pain control (Ogasawara *et al.* 2003). Good palliative care could thereby decrease relatives' stress and workload and have positive effects on the family. However, many studies described how relatives felt forced to check that the patient got good care. These relatives experienced themselves as the patient's advocate, with the task of protecting the patient in different ways (Rogers *et al.* 2000, Steinhauser *et al.* 2000, McGrath 2001, Teno *et al.* 2001).

The structure of care was reported to be of decisive importance regarding relatives' satisfaction with care. Christakis and Iwashyna (2003) showed in a large study that the surviving spouse had an increased length of survival after the patient had received hospice care when compared with other care. Many other studies found that close relatives were very satisfied with hospice/palliative care units (e.g. Lecouturier *et al.* 1999, Morita *et al.* 2002, Rollison & Carlsson 2002, Steele *et al.* 2002, Miceli & Mylod 2003). Ringdal *et al.* (2002) showed that an intervention group that was offered extra support and information in a palliative care program gave higher ratings than the control group to 18 of the 20 items included in a questionnaire and 11 of these differences were significant. Baer and Hanson (2000) described how the quality of care increased, according to relatives, when hospice services were introduced in nursing homes. Teno *et al.* (2004) also showed in a survey study that relatives with hospice home care were more satisfied with the care the dying patient received, in contrast to institutional care where a number of unsatisfied needs were described (Stajduhar 2003). Still another study showed that relatives were satisfied with advanced palliative home care, in a questionnaire with two main questions they described 87% positive and 28% negative aspects (Milberg *et al.* 2003). However, the home environment was sometimes transformed into a hospital-like setting, which could be a disadvantage (Stajduhar 2003).

A number of studies measured relatives' satisfaction with care and reported both satisfaction and dissatisfaction (e.g. Jarrett *et al.* 1999, McRae *et al.* 2000, Morita *et al.* 2002, de Graaff & Francke 2003, Ogasawara *et al.* 2003). In an intervention study at five hospitals, it was found that relatives were satisfied with such factors as pain alleviation (85%), patient comfort (86%), communication about how the patient was feeling (85%) and taking decisions made by the family into consideration (91%). Factors that were related to satisfaction were primarily the structure of care and 'support', which was the intervention included in the study (Baker *et al.* 2000). Rogers *et al.* (2000) also showed that relatives gave high ratings to satisfaction with care in the hospital. Despite this, there were many negative comments in the open-ended responses in this study. Relatives described dissatisfaction with the patient's personal care, including a lack of respect for the patient, needs that had not been met and dissatisfaction with the patient's personal hygiene. Other studies showed that relatives were dissatisfied with hospital care, including factors such as an inadequate supportive environment and rigid hospital routines (Lecouturier *et al.* 1999, Pierce 1999, Dunne & Sullivan 2000, McGrath 2001). Gaps between different care systems were also found

(Dawson & Kristjanson 2003), as well as a lack of follow-up in the community after hospitalization (Perreault *et al.* 2004). Relatives needed more explicit coordination of care.

Being present

This subtheme indicates how relatives showed interest in and tried to be open to and share the patient's world. Relatives described the need for being with the patient, being at hand, being present when the patient died, saying goodbye (Andershed & Ternstedt 1999, Pierce 1999, Wilson & Daley 1999, McGrath 2001, Perreault *et al.* 2004) and even taking part in the care of the dead body (Kwan 2002). Since they knew that time was limited, many relatives wanted to be close to the patient during the time that remained (Strang *et al.* 2002). Many tried to find out what was important to the patient and to do what the patient wanted. It was also found that relatives experienced a feeling of relief if they knew how the patient wanted things to be and if they could fulfil those wishes (Steinhauser *et al.* 2001, Strang *et al.* 2002).

Many studies found that relatives wanted to be involved in the patient's situation despite personal hardship. Involvement took different forms, ranging from being with the patient to carrying out a multitude of tasks (Andershed & Ternstedt 1999, Emanuel *et al.* 1999, Stajduhar & Davies 1999, McGrath 2001, Brazil *et al.* 2003, Brobäck & Berterö 2003, Mok *et al.* 2003, Stajduhar 2003, Perreault *et al.* 2004). Being present involved peaceful times but for some of the relatives this also consisted of too much work and responsibility. Immigrants and relatives from foreign cultures had a need to 'take care of our own' and could refuse professional care (Gelfand *et al.* 2001). Sometimes the woman in the family, who was often the caregiver, was more willing to ask for professional support than the head of the family, who was a man (de Graaff & Francke 2003).

Knowing and communicating

The need for information and communication constituted main themes in many studies (Lecouturier *et al.* 1999, Pierce 1999, Rose 1999, McRae *et al.* 2000, Keegan *et al.* 2001, Miettinen *et al.* 2001, Scott *et al.* 2001, Scott 2001, Gagnon *et al.* 2002, Brobäck & Berterö 2003, Milberg & Strang 2003, King *et al.* 2004). There was a great need for information about the patient's condition, course of illness, symptoms and treatment and about alternatives and available resources, as well as for individualized information for relatives. Information was needed to know what to expect, to make decisions, to plan the day and to prepare for the care of the patient (Gessert *et al.* 2000–2001, Rogers *et al.* 2000, Wilkes *et al.* 2000, Aranda & Peerson 2001, Carter 2001,

McGrath 2001, Steinhauser *et al.* 2001, Hudson *et al.* 2002, Strang *et al.* 2002, Dawson & Kristjanson 2003). This knowledge also made it possible for relatives to function better as caregivers (Rose 1999, Lin *et al.* 2000, Rogers *et al.* 2000, Newton *et al.* 2002, Brobäck & Berterö 2003). It was the view of Medigovich *et al.* (1999) that giving information about details of care and the effectiveness of actions taken by health professionals constituted straightforward interventions. They contended that the more families understood about the patient's care, the more satisfied they would be with the care. Andershed and Ternstedt (1999, 2001) were of the opinion that knowing was a prerequisite for meaningful involvement, since relatives could then more easily choose what they were able/wanted to do and how to do this. Relatives were also afraid of not getting sufficient information and knowledge and they described how they could not have survived without information and/or support (Wilkes *et al.* 2000, Hudson *et al.* 2002). The amount of information a person wants can differ, however, and this can vary and change over time. Rose (1999) reported the existence of 'gatekeepers', meaning that staff members or the patient or relatives can withhold important information from the others. This can make communication more difficult and according to Carter (2001) it can increase relatives' stress. It is difficult to receive information of grave import and Friedrichsen *et al.* (2001) described different roles relatives can assume, ranging from an active prominent role to a passive background role.

The need for communication is especially important in palliative care, as many relatives in today's society are not used to talking about dying and death and many, despite their advanced age, have not been present when someone has died. Bolmsjö and Hermerén (2003) discussed different ethical dilemmas that can arise involving different actors, such as the following example: the husband is worried that he will not be able to take care of his wife, but the patient does not want any outsiders looking after her. Sahlberg-Blom *et al.* (2000) also showed how the patient's self-determination could affect relatives' autonomy. The authors of both studies stressed the importance of continuous communication during the course of illness to identify ethical conflicts. They were also of the opinion that a process including shared decision-making is often ideal when trying to find a solution.

Hinton (1999) assessed the awareness of patients and relatives during the final time and found that relatives were more aware of the situation than the patient. Talking openly in a grave situation can be difficult and trying (Dunne & Sullivan 2000) and can constitute an unfamiliar pattern of communication in some families. Showing mutual consideration for one another has also been described, where the wish is not to make the other person sad and to maintain some

sense of normality (Yates & Stetz 1999, Friedrichsen *et al.* 2001). There were also cultural differences (Koffman & Higginson 2001, de Graaff & Francke 2003). Mok *et al.* (2003) described how the relative and the patient did not openly discuss the fact that the patient was dying, as that could precipitate the patient's death. Fainsinger *et al.* (2003) reported that relatives and patients in Canada wanted full information, in contrast to relatives and patients in Spain. Withholding information was also found in studies describing non-dominant cultures, where it was often the case that relatives and professional knew more than the patient. In these studies, language difficulties were found to be an additional problem. Children in the family often functioned as interpreters for their parents, which made it difficult for parents to pose certain questions (Spruyt 1999, Somerville 2001).

Many studies reported that information and communication were inadequate and insufficient (Dunne & Sullivan 2000, Rogers *et al.* 2000, Bolmsjö & Hermerén 2001, McGrath 2001, Rollison & Carlsson 2002, Yurk *et al.* 2002, Brobäck & Berterö 2003). In a survey study, the majority of relatives' comments concerned dissatisfaction with communication and information (Rogers *et al.* 2000). A number of studies described how relatives had to feel their way forward to get information, they had to be obstinate and ask questions. And information was often difficult to get (Yates & Stetz 1999, Andershed & Ternstedt 2000, 2001, Rogers *et al.* 2000, McGrath 2001). It was also hard for relatives to pose questions when they did not know what to ask about. When they lacked knowledge, felt uninformed and did not know what was going to happen, relatives often felt isolated, disillusioned, frustrated and distressed and had difficulty handling the situation (Pierce 1999, Andershed & Ternstedt 2000, Dunne & Sullivan 2000, Friedrichsen *et al.* 2001, Milberg & Strang 2003, Oldham & Kristjanson 2004). The studies indicated a great need for information and communication and, in addition, Medigovich *et al.* (1999) found that dysfunctional families could benefit from increased communication, thereby avoiding feelings of dissatisfaction with the care. In addition to obtaining information via the professionals and other persons, relatives used the Internet to an increasing extent (Wilkes *et al.* 2000, Dawson & Kristjanson 2003). However, they also reported that finding specific information in this way could be difficult (McGrath 2001).

Support and trusting relationship with the professional

A large number of studies showed that the need for support was of central importance for relatives (Rhodes & Shaw 1999, Keegan *et al.* 2001, Teno *et al.* 2001, Hudson *et al.*

2002, Proot *et al.* 2003, Stajduhar 2003, Strang & Koop 2003, Goldstein *et al.* 2004). Despite that, a lack of support and insufficient understanding from the professional were often reported (Dunne & Sullivan 2000, Bolmsjö & Hermerén 2001, Yurk *et al.* 2002, Perreault *et al.* 2004). Relatives reported experiences of not being involved, feelings of isolation and a lack of preparation. In several studies, this was very clearly described as 'being in the dark' or being 'an outsider', 'not knowing', 'being unsure', or 'having difficulty understanding' (Spruyt 1999, Yates & Stetz 1999, Somerville 2001, Hudson *et al.* 2002, Brobäck & Berterö 2003). Rogers *et al.* (2000) were of the opinion that relatives' dissatisfaction arose from a sense of being devalued, dehumanized or disempowered. The above examples are in clear accord with the metaphor of 'involvement in the dark' that was developed in Andershed and Ternstedt's studies (2000,2001), cp. Main 2002). Involvement in the dark meant isolated involvement on the part of the relative and the metaphor has its basis in insufficient interplay and collaboration. Relatives were involved in the care/situation of the patient, but they had to find out for themselves what they needed to know to be able to support the patient and to find their way in the situation. They lacked guidance and support and felt unprepared for their role (e.g. Hudson *et al.* 2002, Oldham & Kristjanson 2004), which could lead to a caring delay. The interplay was characterized by insufficient respect, avoidance and exclusion and lack of sincerity. The relatives experienced that they were not informed, seen or confirmed by the professional and that they were 'groping around in the dark' when they tried to support the patient (Andershed & Ternstedt 2000, 2001). Other studies described the importance of preparatory skill training and learning how to be a caregiver (Teno *et al.* 2001, Loke *et al.* 2003, Mok *et al.* 2003, Oldham & Kristjanson 2004).

The professional's responsibility for developing a trusting relationship, for an open, positive attitude and for sensitivity to relatives' need for information/communication/education and support was described in many studies, as was the importance of these factors regarding the situation of relatives (Pierce 1999, Rose 1999, Wilson & Daley 1999, Yates & Stetz 1999, Carter 2001, McGrath 2001, Strang *et al.* 2001, Harding *et al.* 2002, Kwan 2002, Yurk *et al.* 2002, Strang & Koop 2003, King *et al.* 2004). The nurse has an important function here (Newton *et al.* 2002) and according to Miettinen *et al.* (2001) the nurse's attitude was dependent on her personal characteristics and knowledge. Based on relatives' statements, Mok *et al.* (2002) described the supportive attitude of the professional using the following words: trust, love, patience, presence, continuity, while other authors mentioned taking time, caring about,

listening, answering questions and seeing the family's needs (e.g. Wilson & Daley 1999, Milberg *et al.* 2003). According to Mok *et al.* (2002), a positive attitude and giving information in an empathetic way were confirming and authorizing (Wilkes *et al.* 2000). Relatives felt positive when they experienced that the professionals goal was the same as their own: a good death (Mok *et al.* 2002). The above examples are in accord with the metaphor of 'involvement in the light' (Andershed & Ternstedt 2000, 2001, cp. Main 2002), which was characterized by the relative being well-informed and experiencing a meaningful involvement based on feelings of mutual trust and confidence between professional and relatives. Relatives described that the professional cared about them and supported them. This increased their possibilities of attaining insight concerning the patient's health situation and participating in the care in a meaningful way. The key concepts that could characterize the professional's attitude were respect, openness, sincerity, confirmation and cooperation. This attitude could be likened to a partnership (Andershed & Ternstedt 2001). Some studies (e.g. Stajduhar & Davies 1999) discussed the importance of partnership and cooperation, while others described the importance of family-centred care (e.g. Rogers *et al.* 2000, Teno *et al.* 2001).

Discussion

In this literature review, it was found that relatives very clearly expressed their need for the patient to feel as good as possible. Being able to offer good care is thereby also of decisive importance for relatives. It was also seen that many relatives had the need to be present, to be at hand and do what was good for the dying person. The fact that this also involved risks was apparent from the findings of many studies, for example, when relatives had to assume a great deal of responsibility for the care in combination with inadequate support from the professional – and this at a time when many people have jobs and other heavy responsibilities.

The family's feelings of security and trust in the professional were found to be of great importance. This should be of particular significance for poorly functioning families with a weaker sense of coherence and with a smaller social network, where the experience of security and trust conveyed by the care professional can be the factor that adds to and strengthens the family's resources.

The results showed that identification of the family's situation and need for support could be easier if the professional's attitude was characterized by respect, openness and collaboration that could thereby inspire trust and security. When the caregiver tries to maintain a curious and

explorative attitude, this can increase the family's possibilities of relating what they consider to be important. This can also increase the professional's readiness to meet families with individual differences and to identify risk families. Insufficient knowledge about the family can result in 'caring in the dark' by the professional, which can increase the risk for a caring delay in relation to both the patient and the relatives. Insufficient knowledge can also increase the risk that families with the greatest needs receive lower priority in terms of care than well-functioning families, especially when resources are limited. Kristjanson and Aoun (2004) are of the opinion that if we do not care for these family members at this difficult time in their lives, they may well become patients later on.

However, studies showing with statistical significance that one care form is better than the other are lacking. The fact that there are no studies in the review with a randomized controlled design may be because of the ethical and methodological difficulties encountered in such studies in palliative care (Grande & Todd 2000). Many of the studies included in the review were of high quality with a clear, logical structure and a relevant and clearly described sample selection, analysis and results. Studies of medium quality were, however, included despite some limitations in selection procedure or description of the analysis, but where the study as a whole was judged as good. More than twice as many studies had a descriptive/explorative design, which is of importance in the assessment of evidence. However, different studies complement one another and in summary, it can be said that the collective evidence is unequivocal: good patient care, communication, information and the attitude of the professional are of decisive importance regarding satisfaction on the part of relatives. The results are also in accord with earlier review studies (Andershed 1999, Kristjanson & White 2002, Hanson 2004, Kristjanson & Aoun 2004, Ternstedt 2004). This is the most solid evidence we have today. What we have here is analytical generalization/evidence, which according to Kvale (1996) means that a well-considered assessment is performed concerning whether the results can provide guidance regarding events in similar situations.

It was found that relatives have multiple and complex needs. Many of the studies point out that relatives' needs differ from those of the patient's and that relatives should be viewed as unique persons. In doing literature reviews, there is a risk that individual, multiple and complex factors are diminished in terms of importance, as material from many different studies is categorized. Most of the qualitative studies demonstrated this complexity, as well as that the illness and dying trajectories were progressive courses where the patient's and relatives' needs and situation could change

from day to day. Additional difficulties can arise when there are many voices in the same family and when ethical dilemmas arise involving different actors. Despite the fact that 'family' was one of the search words and that 'family as the unit of care' is advocated in palliative care, no studies were found that were based on the family.

Thus, there is still a lack of studies involving the family, studies describing ethical dilemmas involving different actors and difficulties that can lead to family conflicts and abusive family relationships, studies in which families at greatest risk for complicated reactions and families that are likely to cope well can be identified. Many studies tended to focus only on negative aspects, meaning that there is also a lack of studies in which death is seen as a natural part of life that can provide positive challenges and implications. In contrast to many previous literature reviews, however, there are more studies that involve non-cancer diagnoses, that focus on non-dominant cultures and in which there are more specific research problems.

In conclusion, it can be said that staff members have a great deal of responsibility for assuring that the patient feels as good as possible, facilitating relatives' involvement based on the family's wishes and limiting the stress and difficulties experienced by the family. The results showed that the relative's satisfaction could depend on the attitude of the professional as well as on good communication, good listening and good information. This can also be viewed as a prerequisite for the professional to get to know the family and to provide 'care in the light.' As a result, there may be a more effective use of time by the professional, as early assessment of families' needs may prevent conflicts and reassure families that their needs are important and will be met (Kristjanson & White 2002), which can result in families that are more secure. An important point of departure for palliative care, irrespective of where it takes place, is to try to support the relative and the patient so they can be involved in their own way at a level that is acceptable to them both.

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Contributions

Study design: BA; data collection and analysis: BA; manuscript preparation: BA.

References

- Adelbratt S & Strang P (2000) Death anxiety in brain tumour patients and their spouses. *Palliative Medicine* **14**, 499–507.
- Andershed B (1999) *The Role of the Family Carer at the End-of-life. A Literature Review* (in Swedish). National Board of Health and Welfare, Stockholm.
- Andershed B (2004) Palliative care. Family members in the context of palliative care. In *The Needs of Family Members. Nursing as an Academic Subject* (Östlinder G ed.) Swedish Society of Nursing, Stockholm, pp. 59–63.
- Andershed B & Ternstedt B-M (1999) Involvement of relatives in the care of the dying in different care cultures. Development of a theoretical understanding. *Nursing Science Quarterly* **12**, 45–51.
- Andershed B & Ternstedt B-M (2000) Being a close relative of a dying person. Development of the concepts: involvement in the light and in the dark. *Cancer Nursing* **23**, 151–159.
- Andershed B & Ternstedt B-M (2001) Development of a theoretical framework of understanding about relatives' involvement in palliative care. *Journal of Advanced Nursing* **34**, 554–562.
- Aranda S & Hayman-White K (2001) Home caregivers of the person with advanced cancer. An Australian perspective. *Cancer Nursing* **24**, 300–307.
- Aranda S & Peerson A (2001) Caregiving in advanced cancer: lay decision making. *Journal of Palliative Care* **17**, 270–276.
- Baer WM & Hanson LC (2000) Families perception of the added value of hospice in the nursing home. *Journal of the American Geriatrics Society* **48**, 879–882.
- Baker R, Wu AW, Teno JM, Kreling B, Damiano AM, Rubin HR, Roach MJ, Wenger NS, Phillips RS, Desbiens NA, Connors AF, Knaus W & Lynn J (2000) Family satisfaction with end-of-life care in seriously ill hospitalised adults. *Journal of the American Geriatrics Society* **48**, S61–S69.
- Bolmsjö I & Hermerén G (2001) Interviews with patients, family and caregivers in amyotrophic lateral sclerosis: comparing needs. *Journal of Palliative Care* **17**, 236–240.
- Bolmsjö I & Hermerén G (2003) Conflicts of interest: experiences of close relatives of patients suffering from amyotrophic lateral sclerosis. *Nursing Ethics* **10**, 186–198.
- Borneman T, Chu DZJ, Wagman L, Ferrell B, Juarez G, McCahill LE & Uman G (2003) Concerns of family caregivers of patients with cancer facing palliative surgery for advanced malignancies. *Oncology Nursing Forum* **30**, 997–1005.
- Brazil K, Bédard M, Willison K & Hode M (2003) Caregiving and its impact on families of the terminally ill. *Aging & Mental Health* **7**, 376–382.
- Brink PJ & Wood MJ (1998) *Advanced Design in Nursing Research*. Saga Publications, Inc, Thousand Oaks.
- Brobäck G & Berterö C (2003) How next of kin experience palliative care of relatives at home. *European Journal of Cancer Care* **12**, 339–346.
- Cameron JL, France R-L, Cheung AM & Stewart DE (2002) Lifestyle interference and emotional distress in family caregivers of advanced cancer patients. *Cancer* **94**, 521–527.
- Carter PA (2001) A not-so-silent cry of help. Older female cancer caregivers' need for information. *Journal of Holistic Nursing* **19**, 271–284.

- Chan CWH & Chang AM (2000) Experience of palliative home care according to caregivers and patients ages in Hong Kong Chinese people. *Oncology Nursing Forum* 27, 1601–1605.
- Christakis NA & Iwashyna TJ (2003) The health impact of health care on families: a matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses. *Social Science & Medicine* 57, 465–475.
- Davies BD, Cowley SA & Ryland RK (1996) The effects of terminal illness on patients and their carers. *Journal of Advanced Nursing* 23, 512–520.
- Dawson S & Kristjanson LJ (2003) Mapping the journey: family carers' perceptions of issues related to end-stage care of individuals with muscular dystrophy or motor neurone disease. *Journal of Palliative Care* 19, 36–42.
- Dunne K & Sullivan K (2000) Family experiences of palliative care in the hospital setting. *International Journal of Palliative Nursing* 6, 170–178.
- Emanuel EJ, Fairclough DL, Slutsman J, Albert H, Baldwin D & Emanuel LL (1999) Assistance from family members, friends, pain care givers and volunteers in the care of terminally ill patients. *The New England Journal of Medicine* 23, 956–963.
- Enyert G & Burman ME (1999) A qualitative study of self-transcendence in caregivers of terminally ill patients. *American Journal of Hospice & Palliative Care* 16, 45–462.
- Fainsinger RL, Nunez-Olarte JM & Demoissac DM (2003) The cultural differences in perceived value of disclosure and cognition: Spain and Canada. *Journal of Palliative Care* 19, 43–48.
- Ferrell BR (1999) Emotional problems in palliative care: the family. In *Oxford Textbook of Palliative Medicine* (Doyle D, Hanks GWC & MacDonal N eds). Oxford University Press, Oxford, pp. 909–917.
- Friedrichsen MJ, Strang PM & Carlsson ME (2001) Receiving bad news: experiences of family members. *Journal of Palliative Care* 17, 241–247.
- Gagnon P, Charbonneau C, Allard P, Soulard C, Dumont S & Fillion L (2002) Delirium in advanced cancer: a psychoeducational intervention for family caregivers. *Journal of Palliative Care* 18, 253–261.
- Gelfand DE, Balcazar H, Parzuchowski J & Lenox S (2001) Mexicans and care for the terminally ill: family, hospice and the church. *American Journal of Hospice & Palliative Care* 18, 391–396.
- Gessert CE, Forbes S & Bern-Klug M (2000–2001) Planning end-of-life care for patients with dementia: roles of families and health professional. *Omega, Journal of Death and Dying* 42, 273–291.
- Goldstein NE, Concato J, Fried TR, Kasl SV & Johnson-Hurzeler R (2004) Factors associated with caregiver burden among caregivers of terminally ill patients with cancer. *Journal of Palliative Care* 20, 38–43.
- de Graaff FM & Francke AL (2003) Home care for terminally ill Turks and Moroccans and factors influencing ease of access and use of service. *International Journal of Nursing Studies* 40, 797–805.
- Grande GE & Todd CJ (2000) Why are trials in palliative care so difficult? *Palliative Medicine* 14, 69–74.
- Grande GE, Todd CJ & Barclay SIG (1997) Support needs in the last year of life: patient and carer dilemmas. *Palliative Medicine* 11, 202–208.
- Grbich C, Parker D & Maddocks I (2001) The emotions and coping strategies of caregivers of family members with a terminal cancer. *Journal of Palliative Care* 17, 30–36.
- Hanson E (2004) Supporting families of terminally ill persons. In *Palliative Care Nursing. Principles and Evidence for Practice* (Payne S, Seymore J & Ingleton C eds). Open University Press, Berkshire, pp. 329–350.
- Harding R, Leam C, Pearce A, Taylor E & Higginson IJ (2002) A multi-professional short-term group intervention for informal caregivers of patients using a home palliative care service. *Journal of Palliative Care* 18, 275–281.
- Harrington V, Lackey NR & Gates MF (1996) Needs of caregivers of clinical and hospice cancer patients. *Cancer Nursing* 19, 118–125.
- Hawkins C (2000) Anorexia and anxiety in advanced malignancy: the relative problem. *Journal of Human Nutrition and Dietetics* 13, 113–117.
- Hinton J (1999) The progress of awareness and acceptance of dying assessed in cancer patients and their caring relatives. *Palliative Medicine* 13, 19–35.
- Hudson P (2004) Positive aspects and challenges associated with caring for a dying relative at home. *International Journal of Palliative Nursing* 10, 58–64.
- Hudson P, Aranda S & McMurray N (2002) Intervention development for enhanced lay palliative caregiver support – the use of focus groups. *European Journal of Cancer Care* 11, 262–270.
- Hull MM (1992) Coping strategies of family caregivers in hospice homecare. *Oncology Nursing Forum* 19, 1179–1187.
- Jarrett NJ, Payne SA & Wiles RA (1999) Terminally ill patients' and lay-carers' perceptions and experiences of community-based services. *Journal of Advanced Nursing* 29, 476–483.
- Keefe FJ, Ahles TA, Porter LS, Sutton LM, McBride CM, Pope MS, McKinstry ET, Furstenberg CP, Dalton J & Baucom DH (2003) The self-efficacy of family caregivers for helping cancer patients manage pain at end-of-life. *Pain* 103, 157–162.
- Keegan O, Mcgee H, Hogan M, Kunin H, O'Brien S & O'Siorain L (2001) Relatives views of health care in the last year of life. *International Journal of Palliative Nursing* 7, 449–456.
- King N, Bell D & Thomas K (2004) Family carers' experiences of out-of-hours community palliative care: a qualitative study. *International Journal of Palliative Nursing* 10, 76–83.
- Koffman J & Higginson IJ (2001) Account of carers' satisfaction with health care at the end of life: a comparison of first generation black Caribbeans and white patients with advanced disease. *Palliative Medicine* 15, 337–345.
- Koop PM & Strang VR (2003) The bereavement experience following home-based family caregiving for persons with advanced cancer. *Clinical Nursing Research* 12, 127–144.
- Kristjanson LJ & Aoun S (2004) Palliative care for families: remembering the hidden patients. *Canadian Journal of Psychiatry* 49, 359–365.
- Kristjanson LJ & Ashcroft T (1994) The family's cancer journey: a literature review. *Cancer Nursing* 17, 1–7.
- Kristjanson LJ & White K (2002) Clinical support for families in the palliative care phase of hematologic or oncologic illness. *Hematology Oncology Clinics North America* 16, 75–762.
- Kristjanson L, Cousins K, White K, Andrews L, Lewin G, Tinnelly C, Asphar D & Greene R (2004) Evaluation of a night respite community palliative care service. *International Journal of Palliative Nursing* 10, 84–90.

- Kvale S (1996) *InterViews. An Introduction to Qualitative Research Interviewing*. Saga Publications, Thousand Oaks.
- Kwan C (2002) Families experiences of the last office of deceased family members in the hospice setting. *International Journal of Palliative Nursing* 8, 266–275.
- Lecouturier J, Jaoby A, Bradshaw C, Lovel T & Eccles M (1999) Lay carers' satisfaction with community palliative care: results of a postal survey. *Palliative Medicine* 13, 275–283.
- Lin C, Wang P, Lai Y, Lin C, Tsai S & Chen TT (2000) Identifying attitudinal barriers to family management of cancer pain in palliative care in Taiwan. *Palliative Medicine* 14, 463–470.
- Loke AY, Liu C-F & Szeto Y (2003) The difficulties faced by informal caregivers of patients with terminal cancer in Hong Kong and the available social support. *Cancer Nursing* 26, 276–283.
- Main J (2002) Management of relatives of patients who are dying. *Journal of Clinical Nursing* 11, 794–801.
- McGrath P (2001) Caregivers' insights on the dying trajectory in hematology oncology. *Cancer Nursing* 24, 413–421.
- McRae S, Caty S, Nelder M & Picard L (2000) Palliative care on Manitoulin Island. Views of family caregivers in remote communities. *Canadian Family Physician* 46, 1301–1307.
- Medigovich K, Porock D, Kristjanson L & Smith M (1999) Predictors of family satisfaction with an Australian palliative home care service: a test of discrepancy theory. *Journal of Palliative Care* 15, 48–56.
- Mehta A & Ezer H (2003) My love is hurting: the meaning spouses attribute to their loved ones' pain during palliative care. *Journal of Palliative Care* 19, 87–94.
- Miceli PJ & Mylod DE (2003) Satisfaction of families using end-of-life care: current successes and challenges in the hospice industry. *American Journal of Hospice & Palliative Care* 20, 360–370.
- Miettinen T, Alaviuhkola H & Pietila A (2001) The contribution of 'good' palliative care to quality of life in dying patients: family members perceptions. *Journal of Family Nursing* 7, 261–280.
- Milberg A, Strang P, Carlsson M & Börjesson S (2003) Advanced palliative home care: next of kin's perspective. *Journal of Palliative Medicine* 6, 747–754.
- Milberg A & Strang P (2004) Exploring comprehensibility and manageability in palliative home care: an interview study of dying cancer patients' informal carers. *Psycho-oncology* 13, 605–618.
- Milberg A, Strang P & Jakobsson M (2004) Next of kin's experience of powerlessness and helpfulness in palliative care. *Support Care of Cancer* 12, 120–128.
- Mok E, Chan F, Chan V & Yeung E (2002) Perception of empowerment by family caregivers of patients with a terminal illness in Hong Kong. *International Journal of Palliative Nursing* 8, 137–145.
- Mok E, Chan F, Chan V & Yeung E (2003) Family experience caring for terminally ill patients with cancer in Hong Kong. *Cancer Nursing* 26, 267–275.
- Morita T, Chihara S & Kashiwaga T (2002) Family satisfaction with inpatient palliative care in Japan. *Palliative Medicine* 16, 185–193.
- Newton M, Bell D, Lambert S & Fearing A (2002) Concerns of hospice patient caregivers. *The ABNF Journal Nov/Dec*, 140–144.
- Ogasawara C, Kume Y & Andou M (2003) Family satisfaction with perception of and barriers to terminal care in Japan. *Oncology Nursing Forum* 30, E100–E105.
- Oldham L & Kristjanson LJ (2004) Development of a pain management programme for family carers of advanced cancer patients. *International Journal of Palliative Nursing* 10, 91–99.
- Payne S, Smith P & Dean S (1999) Identifying the concerns of informal carers in palliative care. *Palliative Medicine* 13, 37–44.
- Perreault A, Fothergill-Bourbonnais F & Fiest V (2004) The experience of family members caring for a loved one. *International Journal of Palliative Nursing* 10, 133–143.
- Pierce SF (1999) Improving end-of-life care: gathering suggestions from family members. *Nursing Forum* 34, 5–14.
- Polit DF & Beck CT (2004) *Nursing Research. Principles and Methods*. Lippincott Williams & Wilkins, Philadelphia.
- Powazki RD & Walsh D (1999) Acute care palliative medicine: psychosocial assessment of patients and primary caregivers. *Palliative Medicine* 13, 367–374.
- Proot IM, Abu-Saad HH, Crebolder HFJM, Goldsteen M, Luker KA & Widdershoven GAM (2003) Vulnerability of family caregivers in terminal palliative care at home: balancing between burden and capacity. *Scandinavian Journal of Caring Sciences* 17, 113–121.
- Rhodes P & Shaw S (1999) Informal care and terminal illness. *Health and Social Care in Community* 7, 39–50.
- Ringdal GI, Jordhøy MS & Kaasa S (2002) Family satisfaction with end-of-life care for cancer patients in a cluster randomized trial. *Journal of Pain and Symptom Management* 24, 53–63.
- Rogers A, Karlsen S & Addington-Hall J (2000) 'All the services were excellent. It is when the human element comes in that things go wrong': dissatisfaction with hospital care in the last year of life. *Journal of Advanced Nursing* 31, 768–774.
- Rollison B & Carlsson M (2002) Evaluation of advanced home care (AHC). The next-of-kin's experiences. *European Journal of Oncology Nursing* 6, 100–106.
- Rose KE (1999) A qualitative analysis of the information needs of informal carers of terminally ill cancer patients. *Journal of Clinical Nursing* 8, 81–88.
- Sahlberg-Blom E, Ternstedt B-M & Johansson J-E (2000) Patient participation in decision making at the end of life as seen by a close relative. *Nursing Ethics* 7, 296–313.
- Schulz R, Mendelsohn AB, Haley WE, Mahoney D, Allen RS, Zhang S, Thompson L & Belle SH (2003) End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *The New England Journal of Medicine* 349, 1936–1942.
- Scott G (2001) A study of family carers of people with a life-threatening illness 2: implications of the needs assessment. *International Journal of Palliative Nursing* 7, 323–330.
- Scott G, Whyler N & Grant G (2001) A study of family carers of people with a life-threatening illness 1: the carers needs analysis. *International Journal of Palliative Nursing* 7, 290–297.
- Somerville J (2001) Palliative care: the experience of informal carers within the Bangladeshi community. *International Journal of Palliative Nursing* 7, 240–247.
- Spruyt O (1999) Community-based palliative care for Bangladeshi patients in east London. Accounts of bereaved carers. *Palliative Medicine* 13, 119–129.
- Stajduhar KI (2003) Examining the perspectives of family members involved in the delivery of palliative care at home. *Journal Palliative Care* 19, 27–35.

- Stajduhar KI & Davies B (1999) Palliative care at home: reflections on HIV/AIDS family caregiving experiences. *Journal of Palliative Care* **14**, 14–22.
- Steele LL, Mills B, Long MR & Hagopian GA (2002) Patient and caregiver satisfaction with end-of-life care: does high satisfaction mean high quality of care? *American Journal of Hospice & Palliative Care* **19**, 19–27.
- Steinhauser KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM & Tulsky JA (2000) In search of a good death: observations of patients, families and providers. *Annual of Internal Medicine* **132**, 825–832.
- Steinhauser KE, Christakis NA, Clipp EC, Mcneilly M, Grambow S, Parker J & Tulsky JA (2001) Preparing for the end of life: preferences of patients, family, physicians and other care providers. *Journal of Pain and Symptom Management* **22**, 727–737.
- Strang VR & Koop PM (2003) Factors which influence coping: home-based family caregiving of persons with advanced cancer. *Journal of Palliative Care* **19**, 107–114.
- Strang S & Strang P (2001) Spiritual thoughts, coping and 'sense of coherence' in brain tumour patients and their spouses. *Palliative Medicine* **15**, 127–134.
- Strang S, Strang P & Ternstedt B-M (2001) Existential support in brain tumour patients and their spouses. *Supportive Care in Cancer* **9**, 625–633.
- Strang VR, Koop PM & Peden J (2002) The experience of respite during home-based family caregiving for persons with advanced cancer. *Journal of Palliative Care* **18**, 97–104.
- Teno JM, Casey VA, Welch LC & Edgman-Levitan S (2001) Patients-focused, family-centered end-of-life medical care: views of the guidelines and bereaved family members. *Journal of Pain and Symptom Management* **22**, 738–751.
- Teno JM, Clarridge BR, Casey V, Welch LC, Wetle T, Shield R & Mor V (2004) Family perspectives on end-of-life care at the last place of care. *JAMA* **291**, 88–93.
- Ternstedt B-M (2004) *Good Care in the End of Life. An Evidence-based Literature Review About Elderly Care* (in Swedish). National Board of Health and Welfare, Stockholm.
- Weitzner MA, McMillan SC & Jacobsen PB (1999) Family caregiver quality of life: differences between curative and palliative cancer treatment setting. *Journal of Pain and Symptom Management* **17**, 418–428.
- Wennman-Larsen A & Tishelman C (2002) Advanced home care for cancer patients at the end of life: a qualitative study of hopes and expectations of family caregivers. *Scandinavian Journal of Caring Sciences* **16**, 240–247.
- Wilkes L, White K & O'Riordan L (2000) Empowerment through information: supporting rural families of oncology patients in palliative care. *Australian Journal Rural Health* **8**, 41–46.
- Wilson SA & Daley BJ (1999) Family perspectives on dying in long-term care settings. *Journal of Gerontological Nursing* **Nov**, 19–25.
- Yates P & Stetz KM (1999) Families awareness of and response to dying. *Oncological Nursing Forum* **26**, 113–120.
- Yurk R, Morgan D, Franey S, Stebner JB & Lansky D (2002) Understanding the continuum of palliative care for patients and their caregivers. *Journal of Pain and Symptom Management* **24**, 459–470.