The Insider and Outsider Perspective

Clinical importance of agreement between patients and nurses in cancer care concerning patients’ emotional distress, coping resources and quality of life

GUNILLA MÅRTENSSON
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Abstract

Background: It is a well-known phenomenon that nurses and other oncology staff have a tendency to ascribe patients with cancer more problems and suffering than the patients themselves report. Aim: The overall aim of the present thesis was therefore to gain increased knowledge and understanding of dis/agreement between patients with cancer and nurses regarding their perception of patients’ situation and of the importance of patient-nurse dis/agreement in clinical practice. Methods: A prospective comparative design was used. Data were collected from a sample of 90 consecutively recruited patient-nurse pairs. Each pair consisted of a patient with cancer, newly admitted to a ward, and a nurse responsible for that patient’s care. Data were collected from the pairs with corresponding self-administered questionnaires on two occasions: directly after the admission interview and on the patient’s third day on the ward. Results: At the group level, a distinct pattern was shown in which nurses ascribed the patients more emotional distress, less coping resources and a lower quality of life than the patients themselves reported. In short, the results revealed the following clinical importance of patient-nurse dis/agreement. With respect to how nurses act in relation to their perceptions of patients’ emotional distress, patient-nurse dis/agreement did not seem to be important; with few exceptions, nurses’ implemented care did not differ when it was directed at more as compared to less distressed patients. Further, nurses’ general tendency to overestimate cancer patients’ problems and suffering had no influence on patients’ satisfaction with received care and nurses’ satisfaction with provided care. However, patients cared for by nurses who underestimated their level of depression were less satisfied with those nurses’ care. In addition, the more frequently the nurse had implemented care characterized by a trusting relationship, the higher patients’ and nurses’ satisfaction with received/provided care. Conclusions: Initial patient-nurse dis/agreement concerning patients’ situation appears to be of little significance to nurses’ caring behaviour and to patients’ and nurses’ subsequent evaluation of received and provided care.

Keywords: cancer care, patient-nurse agreement, emotional distress, coping resources, quality of life, implemented care, trusting relationship, satisfaction with care, work satisfaction

Gunilla Mårtensson, Caring Sciences, Uppsala University, SE-75183 Uppsala, Sweden

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Introduction

This thesis

The focus of the present thesis is on the encounter between two actors in cancer care: (1) the patient; the insider who experiences being diagnosed with, treated for and living with cancer and (2) the caring nurse; the outsider whose responsibility it is to provide care based on the individual patient’s needs. I call them both actors; my standpoint based on fifteen years of clinical experience in cancer care, is that patients are not passive recipients of care. According to laws and legislations, the patient has autonomy and the right to participate in decision-making. Furthermore, it is my clinical experience that patients contribute their personality, lived experiences and willingness in building an involuntary yet mutual relationship with the caring nurse.

The rationale for the present thesis was a need to explore the consequences of a well-known phenomenon, i.e., oncology staffs’ general tendency to ascribe patients with cancer more problems and suffering than the patients themselves report. When I established contact with a research-group investigating possible explanations of this phenomenon in the early 2000s, my curiosity was aroused; especially because questions concerning the clinical importance of dis/ agreement between the patient and the nurse were unanswered in many respects. This knowledge is this thesis planning to add.

I met Hans every second week; our meetings lasted for 3-4 hours. He taught me about the minority population in the north of Sweden, the Lappish culture and their customs; he told me stories and I asked him questions. Once, after we had been seeing each other for a couple of weeks, he said. “It’s strange but I look forward to these meetings”.

Hans had been newly diagnosed with cancer and was being treated with cytostatics. I was his nurse, sitting beside his bed and administering the drugs. I have no key, and do not know whether I overestimated his problems and suffering, but I remember him and our encounter with satisfaction. This story serves as a description of my pre-understanding.
The patient with cancer

The starting point of the present thesis is three variables, presented in this first section: cancer patients’ emotional distress, cancer patients’ coping resources and cancer patients’ quality of life. In the following text, these three variables will occasionally be called cancer patients’ situation.

Cancer is a common disease, and once during a lifetime one-third of the Swedish population will fall ill to cancer. The treatments for cancer have become increasingly efficient; today 60-65% of patients with cancer diagnoses are cured or live with a life-long chronic disease (National Board of Health and Welfare, 2009). Despite this, cancer is a source of fear in society and a threat to life itself for the individual. Fear of cancer is associated with fear that the disease never will be cured (Ekman, Bergbom, Ekman, Berthold, & Mahsneh, 2004; Leydon, Bynoe-Sutherland, & Coleman, 2003). Patients’ emotional reaction to a cancer diagnosis has been shown to be dominated by shock and anxiety (Hjörleifsdottir, Hallberg, Gunnarsdottir, & Bolmsjö, 2007; Kronenwetter et al., 2005; Link, Robbins, Mancuso, & Charlson, 2005). The reported prevalence of anxiety and depression among patients with cancer varies between 10-35% (Aass, Fossa, Dahl, & Moe, 1997; Morse, Kendall, & Barton, 2005; Strong et al., 2007) and is associated with different patient characteristics such as gender, age, cancer type, cancer stage, possibilities to continue daily activities and social life and earlier history of psychiatric problems (Aass et al., 1997; Strong et al., 2007). However, with the exception of depression, cancer patients as a group have not been shown to have a higher prevalence of psychological and psychiatric problems in comparison with the normal population (Osborne, Elsworth, Sprangers, Oort, & Hopper, 2004; van't Spijker, Trijsburg, & Duivenvoorden, 1997).

Thus, during the journey of being diagnosed with, treated for and living with cancer, the patient with cancer is exposed to several events that may induce stress. Patients’ thoughts and behaviour in dealing with and managing stressful events are described by the coping process. In 1984, Lazarus and Folkman presented the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984): the model has later been revised and the parts that concern meaning-making have been elucidated (Folkman, 1997; Folkman & Greer, 2000; Folkman & Moskowitz, 2000). According to this model, the coping process starts with a stressful event (e.g., for the patient with cancer, a threat to life itself and/or disease- and treatment-related problems). The patient’s resources to manage the situation determine whether the event is perceived as harm, a loss, a threat or a challenge. These resources are both external and internal, e.g., social support (Kvåle, 2007; Link et al., 2005), previous experiences, personal beliefs, coping style (Folkman & Greer, 2000; Link et al., 2005; Rustøen, 1995), and efficacy beliefs, i.e., confidence in one’s coping capacity (Folkman & Greer, 2000; Merluzzi & Martinez
Sanchez, 1997a). A strong predictor of managing a specific behaviour has been shown to be the patient’s self-efficacy concerning that behaviour (Bandura, 1997). Patients with cancer who feel more efficacious regarding their coping capacity have reported better psychosocial adjustment (Merluzzi & Martinez Sanchez, 1997a).

Quality of life has been described as the outcome of the coping process, i.e. adjustment or maladjustment (Molassiotis, 1997; Rustøen, 1995). The concept quality of life is subjective and multidimensional (Cella & Tulsky, 1993), and the individual’s perceived health is one factor, among others, that is believed to influence perceived quality of life (Soni & Cella, 2002). Quality of life is appraised by components of physical, functional, psychological, social and existential/spiritual well-being (Brady, Peterman, Fitchett, Mo, & Cella, 1999; Ferrell, Dow, & Grant, 1995). Cancer and cancer treatment are associated with a wide range of symptoms/problems that can affect quality of life: physical (e.g., pain, nausea, fatigue), psychological (e.g., worry, anxiety, depression), social (e.g., loss of role, lack of support) and existential problems (e.g., lack of meaning in life). A review by MacDonald (2001), including both quantitative and qualitative studies, demonstrated that being diagnosed with and treated for cancer affects patients’ well-being in all four core domains. Although being diagnosed with cancer is associated with a range of problems, studies have shown that after the diagnose stage, cancer patients as a group do not, or almost do not, experience lower levels of quality of life than does the normal population (de Haes & van Knippenberg, 1985; Elder et al., 2005; Kessler, 2002; Wettergren, 2002).

In conclusion, despite emotional reactions to the life-threatening disease, an appreciable proportion of patients with cancer seem to adjust to their new situation: they manage to live with the disease and maintain their well-being. Cancer patients’ thoughts and behaviour that serve to maintain well-being can be understood through the Shifting Perspective Model of Chronic Illness (Paterson, 2001; Thorne & Paterson, 1998; Thorne et al., 2002). The model describes living with a chronic illness in terms of an ongoing, two-perspective shifting process. The two perspectives illness-in-the-foreground and wellness-in-the-foreground, have specific functions. The illness-in-the-foreground perspective is characterized by a focus on the sickness, the suffering, the loss, and patients are absorbed by their illness. This perspective has a protective function by helping the patient to learn about and reflect on the disease, but also by eliciting attention from family and caregivers. The wellness-in-the-foreground perspective, on the other hand, is characterized by a focus on one’s self as a person and not as a diseased body. This perspective allows patients to distance themselves from the disease and to focus on emotional, social and spiritual wellness. Patients who have found meaning and hope and a maintained quality of life through the wellness-in-the-foreground perspective may shift perspectives when they, in their contact
with the health care system, have to focus on the disease, on problems/symptoms and side-effects and not on their wellness (Paterson, 2001).

Perceptions of patients’ situation

Several studies have shown discrepancies between patients with cancer and nurses in their perceptions of patients’ emotional distress, coping resources and quality of life. In general, nurses and other oncology staff have a tendency to ascribe patients with cancer more problems and suffering than the patients themselves report. A review by Lampic and Sjödén (2000) including 22 studies demonstrated that nurses (and other oncology staff) predominantly overestimated cancer patients’ emotional distress. Similar findings have been reported in later studies (Ewing et al., 2006; Horton, 2002). While nurses tend to overestimate patients’ emotional distress at the group level (Lampic & Sjödén, 2000), studies investigating agreement between individual patient-nurse pairs have shown mixed results. While many nurses are in agreement with their patients, a substantial proportion of nurses fail to identify clinically significant cases of depression and anxiety as indicated by patient ratings (von Essen, Burstrom, & Sjödén, 1994; Lampic, Peterson, Larsson, & Sjödén, 1996), and they also have shown a tendency to underestimate depression in severely depressed patients (McDonald et al., 1999; Trask et al., 2002).

No previous study has been found that has investigated agreement between individual patient-nurse pairs regarding cancer patients’ coping resources. However, a study comparing cancer patients’ and oncology staffs’ perceptions of hypothetical cancer patients’ confidence in coping with disease- and treatment-related problems demonstrated that the patients reported coping to be less difficult than the staff did (Merluzzi & Martinez Sanchez, 1997b). An additional example of patient-nurse discrepancies regarding coping is described in a study exploring the meaning of “being positive” for patients with cancer who were undergoing treatment. Patients defined “being positive” as maintaining some sort of normal daily living, while nurses who cared for these patients defined the term using words such as acceptance, fighting spirit and looking on the bright side (O'baugh, Wilkes, Luke, & George, 2003).

Nurses’ general tendency to ascribe patients with cancer more problems and suffering than the patients themselves report has also been demonstrated in two reviews investigating quality of life. Nurses/oncology staff have been shown to underestimate cancer patients’ quality of life, and particularly the psychosocial dimensions of quality of life (Sneeuw, Sprangers, & Aaronson, 2002; Sprangers & Aaronson, 1992). Recent empirical studies have shown a similar pattern (Bahrami, Parker, & Blackman, 2008; Steel, Geller, & Carr,
The concordance between patients and nurses/oncology staff is generally higher regarding the more observable physical dimension than regarding the psychosocial dimensions (Brunelli et al., 1998; von Essen, 2004; Sneeuw et al., 2002; Steel et al., 2005). Other studies have shown that nurses in cancer care overlook emotional needs, focus on physical care (Farrell, Heaven, Beaver, & Maguire, 2005) and leave cancer patients with unmet emotional needs (Soothill et al., 2001).

In summary, the known phenomenon is that nurses/oncology staff tend to overestimate cancer patients’ emotional and psychosocial problems. However, there is a paradox here, in that there is also evidence that individual cancer patients’ emotional problems and needs are underestimated and neglected. As described by Jacobsen et al. (1991), there are “three sides of the same coin” (overall group differences, associations between paired data and agreement between pairs). At the group level, when means are compared, differences emerged; nurses as a group have been shown to overestimate cancer patients’ problems and suffering. While studies investigating agreement in individual patient-nurse pairs demonstrate that an appreciable proportion of nurses know their patients well and are in agreement with their patients regarding the patients’ situation. These studies also demonstrate an opposite direction of disagreement, i.e., a substantial proportion of nurses fail to identify cancer patients’ problems. Hence, the aim of the present thesis is to investigate all these phenomenon of patient-nurse dis/agreement (overestimation, agreement and underestimation) regarding the three variables cancer patients’ emotional distress, coping resources and quality of life and their importance to clinical practice.

Possible explanations of patient-nurse dis/agreement

In the nursing literature, knowing the patient is a constantly recurring statement. The concept has been identified as consisting of two components: the nurse’s understanding of the patient’s needs and the nurse’s subsequent selection of individual nursing interventions intended to satisfy the patient’s needs. The nurse’s experience of care, time with the patient and a sense of closeness between the patient and the nurse have been described as important associated factors (Radwin, 1996). Jenny and Logan (1992) found that nurses’ awareness of patients’ perceptions of their situation helps nurses to understand and deal with patients’ concerns. Thus, knowing the patient and patient-nurse agreement regarding the patients’ situation could be considered close concepts. Possible explanations for patient-nurse agreement should be related to the nurse – her self-awareness, reflective abilities and skills i.e., her empathetic abilities (Baillie, 1996; Holm, 1995), communication skills (Baillie, 1996; Sneeuw et al., 2002) and her experience (Radwin, 1996). However, if nurses are to come to understand how patients perceive their own situation, they need their patients’ trust (Heaven &
Maguire, 1997) as well as an adequate amount of time (Kruijver, Garssen, Visser, & Kuiper, 2006), continuity and chronological time (Radwin, 1996). According to Baillie (1996), the presence of empathy involves a complex relationship between the nurse, the patient and the environment, and stress and a heavy workload have a negative influence on empathy.

Discrepancies between patients with cancer and nurses regarding their perceptions of patients’ situation may have several possible explanations, also related to the patient, the nurse and the environment/organization. Patients’ adjustment to the new situation through cognitive and behavioural processes described in the Model of Stress and Coping (Folkman & Greer, 2000; Lazarus & Folkman, 1984) may be difficult for nurses to observe and understand. This assumption is supported by “side findings” from a study by Larsson and co-workers (2003). When interviewing individual patient-nurse pairs about patients’ strategies to “keep a good mood”, they found that one third of the nurses could not even respond to the question. This side finding illustrates the difficulty for an outsider (in that case the nurse) to perceive the insider’s (the patient’s) adaptation to illness. Another explanation for these discrepancies is that patients may withhold from nurses how they feel (Heaven & Maguire, 1997). There could be several reasons for this: Patients may have other close persons (family and friends) to share their concerns with, they may not trust the nurse or they may not want to present themselves as vulnerable or to be exposed (Kvåle, 2007; Sneeuw et al., 2002).

A possible explanation for discrepancies related to nurses, besides the difficulty in observing and understanding patients’ adaptation process, could be expectations concerning cancer patients’ suffering. Such expectations, also called a “requirement of mourning” (Wright, 1983), are based on a projection of how the nurses themselves believe they would experience the same situation. Support for that notion was presented by Lampic et al. (1996). In their study, nurses’ estimation of a specific cancer patient’s anxiety was strongly correlated with the hypothetical anxiety nurses believed they would experience if they were in that patient’s situation. Healthy persons have shown a general tendency to both overestimate problems associated with a certain disease/disability and to underestimate their own ability to handle such a disease/disability (Ubel, Loewenstein, & Jepson, 2003).

Finally, shortcomings in the organization/environment, such as lack of time with the patient and lack of continuity in care, may hinder the development of a sense of closeness between patient and nurse and, as a consequence, reduce nurses’ possibilities to “know the patient” and understand the patient’s situation (Radwin, 1996). Time pressure has been suggested as an explanation for nurses’ limited ability to adequately assess cancer patients’ psychosocial problems (Kruijver et al., 2006).
In conclusion, it is evident that patients and nurses may have different perspectives on the patient’s situation; the patient is the insider, the person who is experiencing the situation, and the nurse is the outsider observing the situation. In the health care system, biological and causal explanations of diseases prevail (Hansson, 2006; Jonsdottir, Litchfield, & Pharris, 2004; Svenaeus, 2003; Watson, 1985). Patients, on the other hand, have their own self-experienced (Hansson, 2006; Svenaeus, 2003) perception of being diagnosed with and living with cancer. In other words, for the patient as an insider, the cancer disease has a self-experienced meaning, and for the nurse as an outsider, the challenge is to gain access to the patient’s self-experienced meaning, so as to understand her/his situation.

The encounter between the patient and the nurse

Patients with cancer often experience a long-term dependency on care and hospitalized patients have a 24-hours-a-day relationship with nurses. Thus, oncology nurses have a front-line role in offering patients support and in meeting every individual’s needs (Botti et al., 2006; Corner, 2002; Ferrell & Coyle, 2008). The relation between the patient and the nurse is asymmetric, i.e. the nurse is performing the care that the patient is dependent on. In every encounter, there is a patient with unique perceptions of his/her problems/needs and expectations of care, and a nurse with individual abilities and skills to understand the patient’s situation, and in turn, to identify and satisfy the patient’s needs. In the present thesis, clinical importance is confined to this encounter between the patient and the nurse in everyday oncology practice.

The caring relationship

Several authors have described the caring relationship (Berg & Danielson, 2007; Dahlberg, 2003; Kasén, 2002; Mok & Chiu, 2004; Watson, 1985). Watson (1985), with her existential and phenomenological perspective, based her caring philosophy on ten caritas factors. One of these factors is the reciprocal trusting relationship between the patient and the nurse. This relationship is described as promoting both expressions of positive and negative feelings and involves congruence and empathy. Here, congruence refers to the nurse’s honesty and authenticity in the encounter with the patient. Through hermeneutical exploration of the concept, Kasén (2002) has made the following contextual descriptions: A caring relationship is a relation, connection, story and touch. The initial assumption is that a caring relationship is an asymmetric relation, because the nurse assumes greater responsibility in the relation. The patient and nurse cannot change positions and the caring relationship is thereby not reciprocal. The caring relationship
is a *connection* formed in the situation of alleviating the patient’s suffering. This connection may start during the important first encounter. By sharing in the patient’s *story* of suffering, the nurse can become an involved co-actor in the process. The caring relationship comprises and *touches* the unity of body, soul and spirit and promotes the patient’s health. Patients describe the caring relationship as something formed on the initiative of nurses, and nurses invite the patients into the relationship. If the patient feels trust and confidence in the nurse, he/she may respond to the nurse’s invitation. The nurse’s interest in and empathy for the patient’s distress and difficulties, but also participation in the patient’s joy, form the essence of a caring relationship. From the perspective of nurses, a caring relationship is described as starting with love and sensitivity to the patient and the nurse’s feeling of responsibility for the patient and for creating a relationship. The first meeting with the patient is essential and important and lays foundation for the development of a caring relationship. If the patient responds to the nurse’s invitation with trust and by telling the nurse her/his story of distress and suffering, the nurse may respond with empathy and a willingness to care. Both patients and nurses stated that not every patient-nurse relation is a caring relationship (Kasén, 2002).

The development of a caring relationship in cancer care was exemplified in a phenomenological study by Dowling (2008). She asked cancer patients undergoing treatment and oncology nurses to describe their interaction. The analysis resulted in three main themes: Developing intimacy, Experiencing intimacy and Outcome of intimacy. In line with Kasén (2002), the first encounter was shown to lay the foundation for nurses’ subsequent identification with and empathy for the patient. Oncology nurses admired and were attracted to patients with a positive outlook and found patients with a detached outlook difficult to engage with (Dowling, 2008), which is comparable with Kasén’s (2002) finding of patients who did not respond to the nurses’ invitation. In contrast to Kasén (2002), but in line with Watson (1985), patients with cancer and oncology nurses have described their relationship as reciprocal (Coffey, 2006; Dowling, 2008; Mok & Chiu, 2004), as a professional friendship and also a need to share personal information in order to develop a trusting relationship (Dowling, 2008). The reciprocal trusting relationship is reported to be an important part of cancer care (Coffey, 2006; Dowling, 2008; Mok & Chiu, 2004; Radwin, Farquhar, Knowles, & Virchick, 2005). Patients have described the trusting relationship as a sense of comfort in that the nurse understands and knows them (Dowling, 2008; Mok & Chiu, 2004). Oncology nurses have reported that a trusting relationship involves knowing the patient and her/his needs and experiencing a sense of unique importance to the patients that brings them satisfaction (Mok & Chiu, 2004; Peteet et al., 1989).
Caring behaviour

Caring involves the ambition to achieve emotional involvement with the patient in order to get in touch with him/her (Dahlberg, 2003; Watson, 1985). However, caring has two dimensions – one aspect is being and the other is doing (Jonsdottir et al., 2004; Norberg & Nilsson, 1997). Caring actions involve an open-minded responsiveness to another’s needs as defined by the other (Noddings, 2003). In several studies using the Caring Assessment Instrument CARE-Q (Larson, 1981), patients with cancer and oncology nurses have reported different perspectives regarding the importance of various caring behaviours (von Essen, & Sjödén, 2003; Larson, 1981; Larsson, Widmark Peterson, Lampic, von Essen, & Sjödén, 1998; Widmark-Petersson, von Essen, & Sjödén, 2000). While oncology nurses have most often prioritized relation-oriented (being) aspects of caring as most important, patients with cancer have most often ranked task-oriented (doing) aspects of caring as most important. Use of the CARE-Q instrument, which split up caring into different caring behaviours, has been criticized for simplifying the complex construct of caring (Kasén, 2002; Lützén & Tishelman, 1991). However, other authors argue that caring is not only a theoretical and elusive construct, but a construct that is difficult to conceptually define and to measure (Beck, 1999; McCance, McKenna, & Boore, 1997; Watson, 2002). The standpoint in the present thesis is that an operationalization of caring is needed if we are to investigate how nurses respond to and act in relation to their perceptions of cancer patients’ situation.

Evaluation of received care and provided care

In order to explore the clinical importance of patient-nurse dis/agreement, we also need to operationalize and measure patients’ and nurses’ evaluations of nurses’ caring behaviours in terms of satisfaction. To further understand the clinical importance of patient-nurse dis/agreement, we need to take patient-nurse general satisfaction with care, as well as, satisfaction with work into account.

Cancer patients’ perspective

Patients’ satisfaction with care is commonly defined as patients’ subjective evaluation of the degree of congruence between their expectations of care and their perceptions of the care they actually received (Eriksen, 1995; Risser, 1975). From this standpoint, dissatisfaction with care appears in situations when patients’ expectations are not fulfilled. However, the concept has been shown to be more complex (Linder-Pelz, 1982a, 1982b; Sitzia & Wood, 1997; Staniszewska & Henderson, 2004). Patients form their expectations of care based on prior experiences (Linder-Pelz, 1982b), and
use previous experiences as a baseline when evaluating satisfaction with care (Staniszewska & Henderson, 2004). Patients’ dependency on care and gratitude and loyalty towards staff (Staniszewska & Henderson, 2005) make detection of negative experiences problematic (Haas, 1999a; Staniszewska & Henderson, 2004).

Care provided by nurses has been reported to be of high importance and to obtain high satisfaction scores when patients with cancer evaluate the received care (Bredart et al., 2007; Von Essen, Larsson, Oberg, & Sjödén, 2002; Sandoval, Levinton, Blackstien-Hirsch, & Brown, 2006; Skarstein, Dahl, Laading, & Fossa, 2002). Several aspects of nurses’ personal qualities and caring behaviour have been shown to predict cancer patients’ satisfaction with care, for instance, nurses’ interpersonal skills (Bredart et al., 2007), courtesy (Sandoval et al., 2006), attention to patients’ psychosocial adaptation to illness (Walker, Ristvedt, & Haughey, 2003), communication skills, availability (Bredart et al., 2007; Skarstein et al., 2002) and technical skills (Bredart et al., 2007; Sandoval et al., 2006).

Further, patients with cancer have reported positive opinions of nurses as a group, with the outcome being that patients feel comforted and cared for, which is important to their recovery (Radwin et al., 2005). In a study by Kvåle (2007), cancer patients reported appreciating it when nurses offered them to talk about difficult emotions, but stated that they most often did not want to talk about difficult feelings concerning the future. To keep living in the present, they wanted to talk with nurses about ordinary things that happen in daily life.

**Oncology nurses’ perspective**

Nurses’ work satisfaction has been identified as a factor that reflects quality in care and that predicts patients’ satisfaction with care (Tzeng, Ketefian, & Redman, 2002). Saane and co-workers (2003) concluded that there is no gold standard of the construct work satisfaction. Following a meta-analysis they operationalized work satisfaction in these eleven domains: work content, autonomy, growth, financial rewards, promotion, supervision, communication, co-workers, meaningfulness, workload and work demands.

Nurses in cancer care have described their work – caring for severely ill patients – as both rewarding and demanding (Corner, 2002; Dowling, 2008; Grunfeld et al., 2005; Kendall, 2006, 2007; Peteet et al., 1989). Their work is described as rewarding particularly because it involves alleviating patients’ suffering (Grunfeld et al., 2005; Kendall, 2006). At the same time their work is demanding, particularly because of their front-line role in offering patients emotional support (Corner, 2002; Tyler & Ellison, 1994). The emotional involvement and the burden inherent in caring for severely ill patients are associated with a risk for work-related stress among oncology nurses (Sherman, Edwards, Simonton, & Mehta, 2006; Vachon, 1998). Work-related stress has been reported to increase with a heavy workload (Barrett &
Yates, 2002; Grunfeld et al., 2005), while experience of cancer care has been described as a factor that helps oncology nurses manage demands and cope with work-related stress (Hinds, Quargnenti, Hickey, & Mangum, 1994; Isikhan, Comez, & Danis, 2004; Peteet et al., 1989). Despite high demands and inherent stressors, nurses in cancer care rate their general work satisfaction as relatively high (Beck-Friis, Strang, & Sjödén, 1991, 1993; Bressi et al., 2008; Grunfeld et al., 2005; Peteet et al., 1989).

Clinical importance of patient-nurse dis/agreement

Thus far, the consequences of patient-nurse dis/agreement concerning patients’ situation for clinical practice have not been studied. With support in the literature, the main assumption is that patient-nurse agreement is a desirable condition. It seems reasonable to assume that when the patient and the nurse are in agreement concerning the patient’s situation, the nurse has an accurate understanding of the patient’s needs and can select appropriate individual nursing interventions directed to these needs. Thereby, patient-nurse agreement is probably the most satisfactory condition for the patient, the insider, as well as for the nurse, the outsider. It also seems reasonable to expect that nurse misjudgement (underestimation or overestimation) of individual cancer patients’ situation has consequences for the care nurses intend to give and for the care the patients actually receive. First, there is a potential risk that patients will not receive the care they need or will receive care they consider irrelevant. Second, if patients have unsatisfied needs or receive irrelevant care, this may influence their satisfaction with care. Third, nurses’ overestimation of patients’ problems may constitute a problem for nurses. With already high demands, a high workload and risk of work-related stress, there is a potential risk that nurses’ overestimation of patients’ problems will increase nurses’ perceived workload and have detrimental consequences for their work satisfaction. Thus, the three outcome variables of clinical importance are: nurses’ planned and implemented care and patients’ as well as nurses’ satisfaction with this care.
Aims

The overall aim of the present thesis was to gain increased knowledge and understanding of dis/agreement between patients with cancer and nurses regarding their perception of patients’ situation and of the importance of patient-nurse dis/agreement in clinical practice.

Study specific aims

Study I: The aims were a) to examine differences, associations and agreement in cancer patients’ and nurses’ ratings of patients’ emotional distress, coping resources and quality of life, and b) to investigate whether the level of patient-nurse agreement was associated with specific characteristics of the patient or the nurse.

Study II: The aim was to investigate nurses’ planning and implementation of individualized patient care in relation to patients’ emotional distress as assessed by nurses. Another aim was to investigate whether nurses and patients perceived the implemented care in a similar manner.

Study III: The aim was to investigate whether patient-nurse dis/agreement concerning patients’ situation was of importance to patients’ satisfaction with care. Another aim was to describe patients’ satisfaction with care and to investigate its’ relationship to patients’ emotional distress.

Study IV: The aim was to investigate whether patient-nurse dis/agreement concerning patients’ situation was of importance to nurses’ satisfaction with provided care. Another aim was to investigate personal factors (related to the patient or the nurse) and occupational factors (workload) of potential importance to nurses’ satisfaction with provided care and nurses’ general work satisfaction.
Methods

Design

Study I has a cross-sectional comparative design and investigates the patients’ situation from both an insider and an outsider perspective. Studies II, III and IV have a prospective comparative design, where Study III takes an insider perspective and Studies II and IV predominantly an outsider perspective.

The problem-solving structure in the Nursing Process model was used as a guide when designing and planning the present thesis (i.e., selection of situation for data collection, selection and development of instruments for data collection). An overview of the design and instrument used is presented in Figure 1. For a detailed description of instruments used, please see pages 22-28.

![Figure 1. An overview of design and selected instruments](image_url)

The Nursing Process (Yura & Walsh, 1988) is a widely used and accepted model used to ensure individual care for each patient. The model involves a problem-solving structure in five sequential and interrelated phases: assessment, diagnosis, planning, implementation and evaluation. The goal of the first phase is to gather information about the patient’s problems and needs - to understand the patient’s own experience of the disease or problem (Iyer, Bernocchi-Losey, & Taptich, 1995) and to identify the patient’s internal and external resources (Carnevali, 1996). According to the model, the nurse, in the encounter with the patient, should confirm what she/he
perceives to be the patient’s needs (Carpenito-Moyet, 2006; Yura & Walsh, 1988). In the second phase, the nurse critically analyses and interprets the patient’s problems and needs and identifies nursing diagnoses. Based on these diagnoses (which should be validated with the patient), nursing care is then planned, implemented and evaluated. All but one phase in the Nursing Process were used according to the model. In the present thesis, the final phase, evaluation, did not concern the outcome of nursing interventions, but instead satisfaction with the received and the provided care as well as work satisfaction (Figure 1).

Sample and setting
The studies comprising the present thesis are based on the same sample. The sample consists of 90 individual patient-nurse pairs. Each pair consists of a patient with cancer, newly admitted to a ward, and a nurse responsible for that patient’s care. A consecutive series of individual patient-nurse pairs were recruited during the study period January to December 2005 (weekdays). The pairs were recruited from three oncology wards and two haematological wards in two hospitals in Sweden (Gävle Hospital and the University Hospital in Uppsala). The organization of nursing care on these wards can be described as team care (i.e. a small group of nurses caring for a small group of patients). The percentage of registered nurses (RNs) in the nursing staff varied between 55% and 100% at the wards, and the nursing staff-patient ratio varied between 1.0 and 1.3.

Patients meeting the following criteria were eligible to participate: age ≥ 18 years, a cancer diagnosis known to the patient, new admittance to the ward, a planned hospital stay of at least three days, ability to speak, read and understand Swedish. Two patients who were considered by the head nurse to be in a too poor condition (physically or mentally) were excluded. Nurses meeting the following criteria were eligible to participate: registered nurses (RN) working regular hours, having worked on the ward for a minimum of three months and scheduled to work three consecutive days.

During the study period, a total of 185 patients were eligible for participation. Of these, 86 patients were not approached, as there was no nurse accessible who met the inclusion criteria, and one patient was included in another research project. Thus, 98 patients were approached and eight declined participation. A total of 90 patients were included and participated in the first data collection (T1) (response rate 92%). Among the nurses who fulfilled the inclusion criteria, three declined participation. In total, 52 nurses participated (response rate 94%). At T1, 16 nurses assessed one patient, 34 nurses assessed two patients and two nurses assessed three patients. At the second assessment after three consecutive days (T2), five patients had been discharged; two patients could not participate due to deteriorated health and
one nurse and one patient from different patient-nurse pairs failed to complete the questionnaire. Out of the 90 individual pairs at T1 (Study 1), 81 pairs were intact at T2 and participated in Study II and IV. Out of the 90 patients who participated at T1 also 82 participated at T2 and were included in Study III. A description of inclusion of patients and nurses, matched to individual patient-nurse pairs, attrition and internal missing data concerning main variables is presented in Figure 2.

Figure 2. Description of inclusion, attrition and internal missing data
Table 1. Characteristics of the participating patients at T1 and T2

<table>
<thead>
<tr>
<th>Patients</th>
<th>T1 (n=90)</th>
<th>T2 (n=82)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>39 (43)</td>
<td>33 (40)</td>
</tr>
<tr>
<td>Male</td>
<td>51 (57)</td>
<td>49 (60)</td>
</tr>
<tr>
<td>Type of cancer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lymphoma</td>
<td>17 (19)</td>
<td>16 (20)</td>
</tr>
<tr>
<td>Myeloma</td>
<td>11 (12)</td>
<td>11 (13)</td>
</tr>
<tr>
<td>Leukaemia</td>
<td>10 (11)</td>
<td>9 (11)</td>
</tr>
<tr>
<td>Hepar/renis</td>
<td>8 (9)</td>
<td>7 (9)</td>
</tr>
<tr>
<td>Sarcoma</td>
<td>7 (8)</td>
<td>7 (9)</td>
</tr>
<tr>
<td>Prostate/testis</td>
<td>5 (6)</td>
<td>5 (6)</td>
</tr>
<tr>
<td>Mouth/oesophagus</td>
<td>5 (6)</td>
<td>4 (5)</td>
</tr>
<tr>
<td>Lung</td>
<td>5 (6)</td>
<td>4 (5)</td>
</tr>
<tr>
<td>Stomach/colon/rectal</td>
<td>4 (4)</td>
<td>4 (5)</td>
</tr>
<tr>
<td>Brain</td>
<td>3 (3)</td>
<td>3 (4)</td>
</tr>
<tr>
<td>Breast</td>
<td>3 (3)</td>
<td>3 (4)</td>
</tr>
<tr>
<td>Cervix/uterus/ovary</td>
<td>2 (2)</td>
<td>-</td>
</tr>
<tr>
<td>Other</td>
<td>10 (11)</td>
<td>9 (11)</td>
</tr>
<tr>
<td>Aim of current treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Palliative</td>
<td>44 (51)</td>
<td>39 (49)</td>
</tr>
<tr>
<td>Curative</td>
<td>43 (49)</td>
<td>40 (51)</td>
</tr>
<tr>
<td>Earlier stay at the ward</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 5 days</td>
<td>42 (47)</td>
<td>39 (48)</td>
</tr>
<tr>
<td>5-10 days</td>
<td>20 (23)</td>
<td>19 (24)</td>
</tr>
<tr>
<td>11-15 days</td>
<td>3 (3)</td>
<td>2 (3)</td>
</tr>
<tr>
<td>&gt;15 days</td>
<td>24 (27)</td>
<td>21 (26)</td>
</tr>
</tbody>
</table>

When numbers do not add to 90 or 82, there is internal missing data

The sample size was based on a power calculation on differences between patients’ and nurses’ ratings of patients’ emotional distress (HADS); with an alpha of 0.05 and a power of 0.80, we needed 80 individual patient-nurse pairs to detect significant differences. In Study II, III and IV, the sample was divided into sub-groups and, thus, the power is limited.

Participating patients had a variety of cancer diagnoses and a mean age of 60 years. The median time since diagnosis was six months (range 1-384 months), and one third of the patients had had relapses. Thirty percent of the patients were living alone, sixty-four percent were married/cohabitated and sex percent were separate living. Additional characteristics of the participating patients are presented above in Table 1.

All but two of the participating nurses (RN) were women. The nurses’ mean age was 39 years, and their experience of cancer care varied between 3 months and 25 years. In thirty-five percent of pairs, the nurse had had earlier
responsibility for their matched patient’s care. In a majority of pairs (62%), the nurse at TI reported knowing the matched patient “not at all”, and in twenty-six of the pairs (33%) the nurse reported knowing the patient “somewhat”. In four pairs (5%), the nurse reported knowing the patient “rather well” and in none of pairs did the nurse know the patient “very well”. Additional characteristics of the participating nurses are presented below in Table 2.

Table 2. Characteristics of participating nurses at T1 and T2

<table>
<thead>
<tr>
<th>Nurses</th>
<th>(n=51) n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>49 (96)</td>
</tr>
<tr>
<td>Male</td>
<td>2 (4)</td>
</tr>
<tr>
<td>Social status</td>
<td></td>
</tr>
<tr>
<td>Single living</td>
<td>10 (20)</td>
</tr>
<tr>
<td>Married/cohabitation</td>
<td>38 (76)</td>
</tr>
<tr>
<td>Separate living</td>
<td>2 (4)</td>
</tr>
<tr>
<td>Education level</td>
<td></td>
</tr>
<tr>
<td>Registered nurse (RN)</td>
<td>37 (74)</td>
</tr>
<tr>
<td>B.Sc. in nursing</td>
<td>8 (16)</td>
</tr>
<tr>
<td>M.Sc. in nursing</td>
<td>1 (2)</td>
</tr>
<tr>
<td>Oncology certified nurse</td>
<td>4 (8)</td>
</tr>
<tr>
<td>Experience of cancer care</td>
<td></td>
</tr>
<tr>
<td>≤2 years</td>
<td>16 (31)</td>
</tr>
<tr>
<td>&gt;2 years</td>
<td>35 (69)</td>
</tr>
<tr>
<td>Workload during the study period</td>
<td></td>
</tr>
<tr>
<td>Much lower</td>
<td>2 (4)</td>
</tr>
<tr>
<td>Quite a bit lower</td>
<td>12 (24)</td>
</tr>
<tr>
<td>Normal</td>
<td>9 (18)</td>
</tr>
<tr>
<td>Quite a bit higher</td>
<td>17 (34)</td>
</tr>
<tr>
<td>Much higher</td>
<td>10 (20)</td>
</tr>
</tbody>
</table>

When numbers do not add up to 51, there is internal missing data

Procedure

The nurses were repeatedly informed about the study at staff meetings. The patients were approached regarding study participation on the day of their arrival at the ward and received written and oral information about the study from the author (GM). After receiving written informed consent, the head nurse matched each patient with a nurse who met the inclusion criteria and who had agreed to participate. In cases where more than one nurse was
eligible, the nurse already planned to have responsibility for the patient’s care or expected to know the patient best was chosen. The following procedure applied to all patient-nurse pairs: The nurse performed an admission interview with the patient according to routine procedure at the ward. Soon after the admission interview (T1), the patient and nurse independently completed corresponding questionnaires concerning the patient’s emotional distress, coping resources and quality of life. Nurses were also requested to identify the patient’s most troublesome physical and emotional problems, and to plan individual nursing interventions that would alleviate these problems. To optimize patients’ possibilities to recognize their matched nurse, each patient was also informed about and personally introduced to her/his matched nurse. During the following three days, that nurse was responsible for the patient’s care. On the patient’s third day at the ward (T2), the patient and nurse independently completed corresponding questionnaires concerning the care the patient had received from the matched nurse, and their satisfaction with this care. The patients also rated their general satisfaction with care and the nurses rated their general work satisfaction. Most patients completed the questionnaires in a separate room during interview administration (by GM). Some patients preferred to complete the questionnaires on their own; GM was then available for questions.

Ethical considerations

In the present thesis, the main ethical questions concern whether the patients and the nurses may experience a breach of integrity. For the patients, this involves being asked personal questions regarding their life situation and being asked to assess the care they received from specific nurses. The nurses, on the other hand, may feel uncomfortable about being evaluated in their work. Considering the opportunity to gain knowledge about potential consequences of patient-nurse dis/agreement for clinical practice, we felt the benefits of the present project far outweighed the possible risks to the participants. To guarantee the participants’ autonomy and integrity, all participants received written and oral information about the study aim, voluntary participation and confidentiality. Moreover, all participants gave their written consent. The study was approved by the Regional Ethical Review Board in Uppsala (Reg.no. 2005:006).
Data collection

Instruments used at the first data collection (T1)

The instruments used at the first data collection were selected according to the following criteria: documented validity and reliability, easy to administrate and, regarding the assessment phase, appropriate to use the nurse version directly after the admission interview. For the assessment phase, the selected instruments cover areas and include items the nurses can reasonable be expected to assess in the admission interview. For example, all areas in the instruments are represented in the assessment phase in the model used for nursing documentation (VIPS) (Ehrenberg, Ehnfors, & Thorell-Ekstrand, 1997). No suitable instrument was found for measuring the diagnosis and planning phases, i.e., how the nurses interpreted patients’ problems and needs and planned to act, thereby development of a study-specific instrument (CPI) was needed. An overview of selected instruments is presented in Table 3. Tests of the instruments’ internal consistency and reference values are presented in Table 4.

Table 3. An overview of the instruments used in Study I-IV

<table>
<thead>
<tr>
<th>Instruments:</th>
<th>HADS</th>
<th>CBI</th>
<th>FACIT-Sp</th>
<th>CPI</th>
<th>CARE-</th>
<th>NSC/PSC</th>
<th>CASC</th>
<th>SWQ</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study I</td>
<td>p/n</td>
<td>p/n</td>
<td>p/n</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study II</td>
<td>n</td>
<td>n</td>
<td>p/n</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study III</td>
<td>p/n</td>
<td>p/n</td>
<td>p/n</td>
<td>p</td>
<td>p</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study IV</td>
<td>p/n</td>
<td>p/n</td>
<td>p/n</td>
<td>n</td>
<td>n</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(T1) = the patients’ day of arrival at the ward; (T2) = after three consecutive days
p=patient-completed instrument; n=nurse-completed instrument

HADS (Study I-IV)

In order to measure patients’ emotional distress, the Hospital Anxiety and Depression Scale (HADS) was chosen, as it is widely used in studies of cancer patients, frequently used in Swedish populations (Arving, Glimelius, & Brandberg, 2008; Lampic et al., 1996; Larsson et al., 2003) and has shown good discriminant and concurrent validity and internal consistency (Bjelland, Dahl, Haug, & Neckelmann, 2002; Herrmann, 1997; Skarstein, Aass, Fossa, Skovlund, & Dahl, 2000). The HADS was developed for patients with a physical illness (Zigmond & Snaith, 1983). The scale consists of two
subscales, anxiety (7 items) and depression (7 items), with four response options (scores from 0=”no distress” to 3=”high distress”). The cut-off points for subscales recommended (Bjelland et al., 2002; Zigmond & Snaith, 1983) are 0-7 for “non-cases”, 8-10 “doubtful cases” and 11-21 “clinically significant cases”. Patients completed the original instrument and nurses answered a corresponding nurse version of the instrument (von Essen et al., 1994), where the words I, my, your are replaced with the patient and the instructions were modified. The nurse version of the HADS has shown satisfactory internal consistency (Table 3) (Lampic et al., 1996). Subjects were asked to base their replies on the past week.

CBI (Study I, III and IV)
In the admission interview, nurses are supposed to identify patients’ internal and external resources. In order to measure patients’ coping resources, the Cancer Behaviour Inventory (CBI) (Merluzzi & Martinez Sanchez, 1997a) was chosen. The CBI has been revised and shown to be reliable (α=0.94; test-retest coefficient 0.74) and to have concurrent and convergent validity (Merluzzi, Nairn, Hegde, Martinez Sanchez, & Dunn, 2001). The instrument measures patients’ self-efficacy for behaviours related to coping with cancer. CBI-long consists of 33 items rated on a nine-point scale (from 1=”not at all confident” to 9=”totally confident”) and allocated to seven factors. In the present studies, five factors were used: Maintaining activity and independence (5 items), Seeking and understanding medical information (5 items), Accepting cancer/maintaining a positive attitude (5 items), Affective regulation (5 items) and Seeking support (3 items). Two factors containing items about treatment side-effects (e.g. hair loss, nausea) were excluded because active treatment was not an inclusion criterion in the present thesis. The CBI was translated to Swedish according to the following procedure. A translator (teacher in English) with Swedish as his native language translated the English version into Swedish. The back-translation to English was performed by an English-speaking professional translator together with a native English-speaking researcher in the area. The translators then discussed a few discrepancies in order to reach consensus. The Swedish version was tested in a pilot study with 18 patients with blood malignancies in autumn 2004; Cronbach’s alpha was 0.70-0.90 and readability was good. Patients completed the original instrument and nurses answered a corresponding version of the instrument, where the words I, my, your were replaced with the patient and the instructions were modified. Subjects were asked to base their replies on the present or the near future.

FACIT-Sp (Study, I, III and IV)
In order to measure patients’ quality of life, the Functional Assessment of Chronic Illness Therapy- Spiritual Well-being (FACIT-Sp) (Brady et al., 1999) was chosen. The reason for choosing this instrument was twofold:
According to Swedish legislation, the goal of nursing is to facilitate physical, psychological, social and spiritual health, and FACIT-Sp covers these domains and has demonstrated good internal consistency and convergent validity (Brady et al., 1999; Peterman, Fitchett, Brady, Hernandez, & Cella, 2002). The instrument includes the widely used “core” scale Functional Assessment of Chronic Illness Therapy-General (FACT-G) (Cella et al., 1993), with the addition of a spiritual subscale (Brady et al., 1999). A recent meta-analytic review covering 344 studies using the FACT-G demonstrated evidence for acceptable reliability across studies (Victorson, Barocas, Song, & Cella, 2008). FACIT-Sp consists of 39 items on a 5-point Likert scale (0-4). The instrument has five subscales: Physical well-being (7 items), Social well-being (7 items), Emotional well-being (6 items), Functional well-being (7 items) and Spiritual well-being (12 items). A Swedish version of FACIT-Sp was provided by the organization FACIT (www.facit.org). The organization certifies the Swedish version’s reliability and validity, but no data on these tests are available. Patients completed the original instrument and nurses answered a corresponding version of the instrument, where the words I, my, your were replaced with the patient and the instructions were modified. A proxy version of FACT-G has shown satisfactory internal consistency, except for the subscale Social well-being (Table 3) (Steel et al., 2005). Subjects were asked to base their replies on the past week.

CPI (Study II)

A study-specific instrument, the Care Planning Instrument (CPI), was developed for assessment of nurses’ identification and care planning regarding individual patients’ physical and emotional problems. The instrument contains possibilities to identify two physical and two emotional problems. Only data on nurses’ identification and care planning regarding the emotional problem that the nurse rated as troubling the patient most are reported in the present thesis (Study II). The CPI includes the following five steps: 1) The nurse was asked to identify her matched patient’s most troublesome emotional problem (open question) and 2) to rate how troublesome that problem is for the patient (from 0= “not at all” to 6=”unbearable”). After this, the nurse was requested 3) to plan the most important nursing intervention for the identified problem (open question) and 4) to rate her confidence in implementing the planned nursing intervention (from 0=“not at all confident” to 6=“totally confident”). Finally, 5) the nurse rated her confidence in whether the planned nursing intervention would alleviate the patient’s problem (from 0=“not at all confident” to 6=“totally confident”). Nurses’ individually planned nursing interventions were transferred in handwriting to the patients’ and the nurses’ questionnaires at T2, and then evaluated by both patients and nurses along with and in the same manner as the instrument CARE-How Often (presented below). The CPI was tested in a pilot study with nurses in cancer care (n=8).
and judged to be appropriate for care planning, have good face validity and to be easy to understand. In addition, at T1, both nurses and patients completed a form covering personal characteristics.

Instruments used at the second data collection (T2)
The instruments used at the second data collection were selected according to the following criteria; documented validity and reliability, easy to administrate and covering assessment of individual nurses’ implemented care, evaluation of this care in terms of satisfaction, as well as general satisfaction with care and work. No suitable instrument was found to evaluate satisfaction with individual nurses’ implemented care, and thereby development of study-specific instruments was needed (NSC and PSC). Tests of the instruments’ internal consistency and existing reference values are presented in Table 4.

CARE-How Often (Study II)
In order to measure individual nurses’ implemented care, the Caring Assessment Instrument CARE-How Often was chosen, as it has been shown to be a reliable instrument for measuring occurrence of caring behaviours (Von Essen & Sjödén, 1995). The CARE-How Often was developed on the basis of CARE-Q (Larson, 1981), which has shown good psychometric properties. The CARE-How Often consists of 50 caring behaviours rated on a seven-point scale (from 1=very seldom to 7=very often, with the present study-specific addition of the response alternative 0=not applicable). The items are categorized into six subscales: Accessible (6 items), Explains and facilitates (6 items), Comforts (9 items), Anticipates (5 items), Trusting relationship (16 items) and Monitors and follows through (8 items). The patient and nurse were asked “How often has/have the nurse (XX)/you performed the following caring behaviours when caring for me/patient (XX) during the past three days?” Both the patient and the nurse versions of the CARE-How Often have shown cross-cultural and content validity as well as satisfactory internal consistency (von Essen & Sjödén, 1995).

In addition, for each patient-nurse pair, the nurse’s individually planned nursing interventions for alleviating the patient’s emotional problem (T1) were evaluated along with, and in the same manner as, the CARE-How Often. Nurses were also requested to rate whether they had implemented the individually planned nursing intervention as planned and any reason for not doing so. Further, nurses were asked to rate their workload during the study period in comparison with the three previous months (scores from “much lower” to “much higher”) (Table 2).
NSC and PSC (Study III and IV)
Two study-specific questionnaires, called the Nurse-specific Satisfaction with Care (NSC) and Patient-specific Satisfaction with Care (PSC), were designed to measure patients’ satisfaction with the care received from a specific, named nurse and nurses’ satisfaction with provided care to a specific, named patient. Note that the patient evaluated the nurse, and completed the NSC, and the nurse evaluated care directed to an individual patient, and completed the PSC. The questionnaires were developed on the basis of the subscales in the instrument Caring Assessment Instrument CARE-Q (Larson, 1981) (presented above) and measure both task and relational aspects of caring. The questionnaires include eight items ranked on a seven-point scale (0=not at all to 6=to a very high degree), where 6 represents the highest satisfaction. Examples of items are: “How satisfied are you with the support and comfort you received from the nurse” and “How satisfied are you with the support and comfort you have given to the patient?” Patients and nurses were asked to base their replies on the care received from (NSC)/given to (PSC) a specific named nurse/patient during the past three days. The questionnaires were tested in a pilot study in surgical care (60 nursing student-patient pairs) and showed good readability and reliability (Table 4).

CASC (Study III)
In order to measure patients’ general satisfaction with care, the Comprehensive Assessment of Satisfaction with Care (CASC) SF version 4.0 (Bredart et al., 1998; Bredart et al., 2001; Bredart et al., 2003) was chosen. The CASC has shown good psychometric properties in different countries, including Sweden (Bredart et al., 2001; Bredart et al., 2003). The CASC consists, after revision, of 32 items and measures patients’ satisfaction with the medical and nursing care and services received. All items are rated on a 5-point scale (1=poor to 5=excellent). The items are divided into 14 subscales. In Study III, patients’ satisfaction with nurses’ care was assessed using the following subscales: Nurses’ technical skills (3 items), Nurses’ interpersonal skills (3 items), Nurses’ information provision (3 items) and Nurses’ availability (2 items). In addition, the subscale General satisfaction (1 item) was utilized. All subscale scores were transformed to 0-100. Higher scores represent a higher level of satisfaction. Patients were asked to base their replies on the past three days.

Open questions regarding received care (Study III)
After interviewing twelve patients, one patient made us aware of the assumptions described by Haas (1999b) and Staniszewska and Henderson (2004), i.e., that satisfaction with care and dissatisfaction with care seem to be two different concepts that do not exist along the same continuum. This
female patient answered the questionnaires (NSC and CASC) and gave high ratings for her satisfaction with care. After that, she spontaneously described the care she had received, and her narrative was full of negative experiences. Therefore, two additional open questions were posed to the subsequent participants: 1) Will you please, describe in your own words the care you have received during the past three days? 2) If you were allowed to make a wish, would you want anything about your care to be different? The patients’ answers were written down by the author (GM) and not tape-recorded.

**SWQ (Study IV)**

Nurses’ general work satisfaction was measured using the Satisfaction with Work Questionnaires (SWQ) (Engström, Ljunggren, Lindqvist, & Carlsson, 2006). The SWQ is re-developed from an earlier questionnaire used by Beck-Friis and co-workers in cancer care (Beck-Friis et al., 1991, 1993). The instrument includes three dimensions: Psychosocial aspects of job satisfaction, Quality of care and Psychosomatic health aspects. The dimension Psychosocial aspects of job satisfaction consists of 49 items allocated to 8 factors: Personal development (9 items), Workload (11 items), Criticism (5 items), Expectations and demands (6 items), Cooperation (5 items), Internal motivation (5 items), External motivation (4 items) and Position in the group (4 items). The dimension Quality of care consists of 24 items allocated to four factors: Nursing and medical care (8 items), Communication obstacle (7 items), Documentation (5 items) and Communication ability (4 items). Finally, the dimension Psychosomatic health aspects consists of 19 items and two factors: Sleep disturbance (9 items) and Perceived stress (10 items). All items are rated on a 5-point scale (0-4). All factor scores are transformed to 0-100. Higher scores represent a higher level of satisfaction. The SWQ has shown construct and known group validity and satisfactory internal consistency in elderly care (Engström et al., 2006). Nurses who participated twice (i.e., assessed two patients) completed the SWQ only once, in connection with their first study participation.
Table 4. Cronbach’s alpha values in the present samples and reference values

<table>
<thead>
<tr>
<th>Instruments</th>
<th>Subscales/factors (number of items)</th>
<th>Patients The present sample</th>
<th>Reference values</th>
<th>Nurses The present sample</th>
<th>Reference values</th>
</tr>
</thead>
<tbody>
<tr>
<td>HADS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Anxiety subscale (7)</td>
<td>0.86</td>
<td>0.86</td>
<td>0.87</td>
<td>0.83</td>
</tr>
<tr>
<td></td>
<td>Depression subscale (7)</td>
<td>0.81</td>
<td>0.72</td>
<td>0.89</td>
<td>0.76</td>
</tr>
<tr>
<td>CBI</td>
<td>Maintain activity and independence (5)</td>
<td>0.74</td>
<td>0.86</td>
<td>0.89</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Seeking and understanding medical information (5)</td>
<td>0.84</td>
<td>0.88</td>
<td>0.87</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Accepting cancer/maintaining a positive attitude (5)</td>
<td>0.76</td>
<td>0.86</td>
<td>0.91</td>
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</tr>
<tr>
<td></td>
<td>Affective regulation (5)</td>
<td>0.38</td>
<td>0.81</td>
<td>0.63</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Seeking support (3)</td>
<td>0.62</td>
<td>0.80</td>
<td>0.83</td>
<td></td>
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<tr>
<td>FACIT-Sp</td>
<td>Physical well-being (7)</td>
<td>0.78</td>
<td>0.84</td>
<td>0.80</td>
<td>0.90</td>
</tr>
<tr>
<td></td>
<td>Social well-being (7)</td>
<td>0.62</td>
<td>0.78</td>
<td>0.86</td>
<td>0.51</td>
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<tr>
<td></td>
<td>Emotional well-being (6)</td>
<td>0.82</td>
<td>0.80</td>
<td>0.84</td>
<td>0.69</td>
</tr>
<tr>
<td></td>
<td>Functional well-being (7)</td>
<td>0.82</td>
<td>0.86</td>
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<td>0.90</td>
</tr>
<tr>
<td></td>
<td>Spiritual well-being (12)</td>
<td>0.87</td>
<td>0.84</td>
<td>0.87</td>
<td>-</td>
</tr>
<tr>
<td>CARE-How Often</td>
<td>Accessible (6)</td>
<td>0.59</td>
<td>0.69</td>
<td>0.74</td>
<td>0.76</td>
</tr>
<tr>
<td></td>
<td>Explains and facilitates (6)</td>
<td>0.63</td>
<td>0.74</td>
<td>0.80</td>
<td>0.59</td>
</tr>
<tr>
<td></td>
<td>Comforts (9)</td>
<td>0.61</td>
<td>0.83</td>
<td>0.65</td>
<td>0.86</td>
</tr>
<tr>
<td></td>
<td>Anticipates (5)</td>
<td>0.27</td>
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<td>0.72</td>
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<td></td>
<td>Trusting relationship (16)</td>
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<td>0.86</td>
</tr>
<tr>
<td></td>
<td>Monitors and follows through (8)</td>
<td>0.50</td>
<td>0.80</td>
<td>0.67</td>
<td>0.79</td>
</tr>
<tr>
<td></td>
<td>NSC/PSC</td>
<td>0.92</td>
<td>0.93</td>
<td>0.89</td>
<td>0.90</td>
</tr>
<tr>
<td>CASC</td>
<td>Technical skills (3)</td>
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<td>0.94</td>
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</tr>
<tr>
<td></td>
<td>Interpersonal skills (3)</td>
<td>0.84</td>
<td>0.92</td>
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<tr>
<td></td>
<td>Information provision (3)</td>
<td>0.84</td>
<td>0.95</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Availability (2)</td>
<td>0.76</td>
<td>0.86</td>
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<td>SWQ</td>
<td>Personal development (9)</td>
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<td>0.72</td>
<td>0.84</td>
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<td>Workload (11)</td>
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<td>0.80</td>
<td>0.86</td>
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</tr>
<tr>
<td></td>
<td>Criticism (5)</td>
<td></td>
<td>0.81</td>
<td>0.74</td>
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<tr>
<td></td>
<td>Expectations and demands (6)</td>
<td></td>
<td>0.80</td>
<td>0.71</td>
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<tr>
<td></td>
<td>Cooperation (5)</td>
<td></td>
<td>0.85</td>
<td>0.80</td>
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<tr>
<td></td>
<td>Internal motivation (5)</td>
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<td>0.64</td>
<td>0.69</td>
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<td>External motivation (4)</td>
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<td>0.59</td>
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<td></td>
<td>Position in group (4)</td>
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<td>0.54</td>
<td>0.52</td>
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</tr>
<tr>
<td></td>
<td>Nursing and medical care (8)</td>
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<td>0.84</td>
<td>0.85</td>
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</tr>
<tr>
<td></td>
<td>Communication obstacle (7)</td>
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<td>0.72</td>
<td>0.81</td>
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</tr>
<tr>
<td></td>
<td>Documentation (5)</td>
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<td>0.70</td>
<td>0.86</td>
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</tr>
<tr>
<td></td>
<td>Communication ability (4)</td>
<td></td>
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<td>0.80</td>
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<tr>
<td></td>
<td>Sleep disturbance (9)</td>
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<td>0.93</td>
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<tr>
<td></td>
<td>Perceived stress symptoms (10)</td>
<td></td>
<td>0.72</td>
<td>0.87</td>
<td></td>
</tr>
</tbody>
</table>

1) = reference values patient samples; HADS (Lampic et al., 1996); CBI (Merluzzi et al., 2001); FACIT-Sp (Whitford, Olver, & Peterson, 2008); CARE-How Often (von Essen & Sjödén, 1995); NSC (pilot study); CASC (Bredart et al., 2005). 2) = reference values nurse/staff samples; HADS (Lampic et al., 1996); FACIT-Sp (Steel et al., 2005); CARE-How Often (von Essen & Sjödén, 1995); PSC (pilot study); SWQ (Engström et al., 2006).
Data analyses

Data were analysed using SPSS version 15.0. Missing data were replaced according to the manuals for CBI, FACIT-Sp, and CASC, i.e., missing data were replaced with the mean for the individual in the subscale. Provided that more than half of the items in a subscale had been answered, missing data for HADS were replaced with the mean for the individual. For CARE-How Often, NSC/PSC and SWQ missing data were replaced with the mean of the item for the group.

Study I

Differences between patients’ and nurses’ ratings of the patients’ emotional distress (HADS), coping resources (CBI) and quality of life (FACIT-Sp) were calculated using dependent t-tests. To examine the statistical magnitude of observed differences, effect sizes (ES) for dependent groups were calculated using Cohen’s $d$ (Cohen, 1988). Associations between patient and nurse ratings were calculated using Pearson’s correlation coefficient ($r$). To calculate the level and direction of the dis/agreement in individual patient-nurse pairs, new categorical variables were developed for all subscales and total scales and subgroups were identified. This procedure is briefly presented in Figure 3 and in detail in the article of Study I (Mårtensson, Carlsson, & Lampic, 2008). To investigate whether the level of patient-nurse dis/agreement was associated with specific characteristics of the patient or the nurse, differences were calculated using crosstabs 3 x 2 and Chi$^2$ tests (with the following-up tests; Adjusted standardized residuals > 3) (Agresti, 2002). Significance levels of 0.05 were set for all tests.
Subscale scores and total scores for each instrument (HADS, CBI, FACIT-Sp) were transformed to 0-100.

Differences between nurse and patient ratings were calculated for each subscale and for the total scales (nurse score minus patient score).

New categorical variables were developed (Underestimation= a difference in scoring <-15; Agreement= a difference in scoring between -15 to +15; Overestimation= a difference in scoring >15) for each subscale and the total scales.

Following the above procedure, the pairs were grouped into three categories: a) A group demonstrating Consistent agreement (the nurse and the patient were in agreement concerning the patient’s emotional distress, coping resources and quality of life). b) A group demonstrating Consistent disagreement (the nurse consistently overestimated the patient’s emotional distress and underestimated coping resources and quality of life). c) A group of Mixed agreement (the nurse under- or overestimated one or two of the three scales).

Figure 3. Procedure of calculating dis/agreement and identifying subgroups

Study II

The nurses identified the patients’ emotional problems and described them in an open response format. These statements were analysed and qualitatively sorted into seven categories. The individually planned nursing interventions (open response format) were categorized into the keywords for nursing interventions described in the VIPS model (Ehnfors et al., 1998). Frequencies, percentages, mean values and standard deviations were used for description. Associations between nurse and patient ratings of implemented care were calculated using Pearson’s correlation coefficient (r). Because data showed a normal distribution (Kolmogorov-Smirnov test) independent sample t-tests were used for comparisons between subgroups of nurses and patients, respectively. Corresponding non-parametric tests (Mann-Whitney) were also performed and supported the findings. Significance levels of 0.05 were set for all tests.

Study III

In order to investigate whether patient-nurse dis/agreement was of importance to patients’ satisfaction with care the subgroups identified in Study I were used. Differences in satisfaction with care (NSC, CASC) between subgroups were calculated using the Kruskal-Wallis tests in cases of small sample sizes in subgroups, and otherwise (because data showed a normal distribution according to Kolmogorov-Smirnov test) with analysis of
variance (ANOVA). Independent t-tests were used to compare satisfaction with care (NSC) between patients with high versus low levels of anxiety and depression (HADS). Significance levels of 0.05 were set for all tests.

Data from the two open questions were analysed in the following order. The text, consisting of patients’ responses to the open questions, was read through several times in order to obtain an overall understanding. Then the patients’ statements were divided into meaning units and labelled with a code. Codes were grouped together into subcategories and categories by the first author. The subcategories and categories describe the obvious and manifest content of the patients’ statements. All authors finally discussed the categorization until consensus was reached.

Study IV

In order to investigate whether nurse-patient dis/agreement was of importance to nurses’ satisfaction with provided care, the subgroups identified in Study I were used. Due to the small sample sizes, non-parametric tests were chosen. The Kruskal-Wallis test and the Mann-Whitney test were used to calculate differences in satisfaction with care between nurses in agreement vs. disagreement with their matched patients concerning the patients’ situation. Associations between nurse ratings of patients’ HADS, CBI and FACIT-SP and nurses’ satisfaction with provided care (PSC) were calculated using Spearman’s correlation coefficient. The Mann-Whitney test was used to calculate situational, personal and occupational factors of importance to nurses’ satisfaction with provided care (PSC) and general work satisfaction (SWQ). Significance levels of 0.05 were set for all tests.
Results

Study I

The results showed significant group differences between patients’ and nurses’ ratings of patients’ emotional distress, coping resources and quality of life (except for the subscale Physical well-being). The ES were large (>0.80) (Cohen, 1988) for three of five CBI subscales (Maintenance activity and independence, Seeking and understanding medical information, and Affective regulation) and for Social well-being (FACIT-SP). The correlations between patient and nurse ratings were ≤ 0.53 and the percentage of agreement was between 36% and 60% in the subscales (Table 5). The results indicate a distinct pattern in which nurses overestimate patients’ emotional distress (HADS) and underestimate patients’ coping resources (CBI) and quality of life (FACIT-Sp). The findings demonstrated that a nurse who overestimated a patient’s emotional distress and underestimated his/her resources for handling the situation was also likely to underestimate the patient’s quality of life. Patient-nurse pairs demonstrating consistent agreement differed from the remaining pairs concerning the following aspects: They had a larger percentage of nurses with an advanced education and previous responsibility for their patient’s care, and they had a higher frequency of patients who had previously received care at the ward for more than five days. Despite nurses’ overestimation of patients’ emotional distress on the group level, also a substantial number of clinically significant cases of anxiety and particularly depression (as indicated by patient ratings) were found that the nurses had failed to identify.
Table 5. Overview of differences, associations and agreement between patient and nurse ratings

<table>
<thead>
<tr>
<th>Variables</th>
<th>Patients m (SD)</th>
<th>Nurses m (SD)</th>
<th>t-value</th>
<th>p-value</th>
<th>ES(^a)</th>
<th>(r)</th>
<th>Under* (%)</th>
<th>Agree* (%)</th>
<th>Over* (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HADS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety sub-scale</td>
<td>5.5 (4.5)</td>
<td>7.0 (4.1)</td>
<td>-3.05</td>
<td>0.003</td>
<td>0.35</td>
<td>0.44</td>
<td>13</td>
<td>54</td>
<td>33</td>
</tr>
<tr>
<td>Depression sub-scale</td>
<td>5.3 (4.1)</td>
<td>6.2 (4.2)</td>
<td>-2.01</td>
<td>0.047</td>
<td>0.22</td>
<td>0.46</td>
<td>17</td>
<td>59</td>
<td>24</td>
</tr>
<tr>
<td><strong>CBI</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maintenance activity and independence</td>
<td>34.9 (7.5)</td>
<td>27.2 (9.3)</td>
<td>7.44</td>
<td>&lt;0.001</td>
<td>-0.92</td>
<td>0.34</td>
<td>55</td>
<td>36</td>
<td>10</td>
</tr>
<tr>
<td>Seeking and understanding medical information</td>
<td>36.3 (7.3)</td>
<td>29.7 (9.0)</td>
<td>6.21</td>
<td>&lt;0.001</td>
<td>-0.81</td>
<td>0.26</td>
<td>51</td>
<td>40</td>
<td>9</td>
</tr>
<tr>
<td>Accepting cancer/ maintaining a positive attitude</td>
<td>35.0 (6.8)</td>
<td>29.4 (8.6)</td>
<td>6.10</td>
<td>&lt;0.001</td>
<td>-0.73</td>
<td>0.39</td>
<td>50</td>
<td>43</td>
<td>7</td>
</tr>
<tr>
<td>Affective regulation</td>
<td>29.5 (5.7)</td>
<td>23.7 (6.0)</td>
<td>6.63</td>
<td>&lt;0.001</td>
<td>-0.98</td>
<td>0.05</td>
<td>44</td>
<td>50</td>
<td>6</td>
</tr>
<tr>
<td>Seeking support</td>
<td>19.0 (5.0)</td>
<td>17.3 (5.3)</td>
<td>2.84</td>
<td>0.006</td>
<td>-0.34</td>
<td>0.36</td>
<td>32</td>
<td>52</td>
<td>16</td>
</tr>
<tr>
<td><strong>FACIT-Sp</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical well-being</td>
<td>18.2 (6.2)</td>
<td>18.1 (5.8)</td>
<td>0.86</td>
<td>0.932</td>
<td>-0.00</td>
<td>0.52</td>
<td>22</td>
<td>60</td>
<td>19</td>
</tr>
<tr>
<td>Social well-being</td>
<td>22.3 (3.7)</td>
<td>18.1 (5.1)</td>
<td>7.57</td>
<td>&lt;0.001</td>
<td>-0.95</td>
<td>0.32</td>
<td>46</td>
<td>49</td>
<td>5</td>
</tr>
<tr>
<td>Emotional well-being</td>
<td>17.9 (4.9)</td>
<td>14.9 (5.0)</td>
<td>5.32</td>
<td>&lt;0.001</td>
<td>-0.60</td>
<td>0.44</td>
<td>43</td>
<td>48</td>
<td>9</td>
</tr>
<tr>
<td>Functional well-being</td>
<td>14.8 (6.4)</td>
<td>13.1 (6.2)</td>
<td>2.66</td>
<td>0.009</td>
<td>-0.28</td>
<td>0.53</td>
<td>26</td>
<td>57</td>
<td>17</td>
</tr>
<tr>
<td>Spiritual well-being</td>
<td>32.0 (8.9)</td>
<td>27.4 (7.3)</td>
<td>4.79</td>
<td>&lt;0.001</td>
<td>-0.56</td>
<td>0.40</td>
<td>35</td>
<td>56</td>
<td>9</td>
</tr>
</tbody>
</table>

\(^a\) ES = effect size; * Under = nurse underestimation, differences between nurse and patient ratings > minus 15, Agree = agreement, differences between nurse and patient ratings -15 to 15, Over = nurse overestimation, differences between nurse and patient ratings > 15
Study II

The results showed that the nurses most frequently identified problems categorized as Worry as being individual patients’ most troublesome emotional problem. Some sort of Support and Information were the nurses’ most frequent nursing interventions for alleviating patients’ emotional problems. The nurses were rather confident about their ability to implement the planned intervention, and were confident that the planned intervention would alleviate the patient’s problem. Nurse-patient perceptions of implemented care demonstrated weak correlations for these individually planned interventions (from CPI) as well as for nurse caring behaviour in general (CARE-How Often) (Table 6). With few exceptions, nurse self-reports did not indicate any significant differences in nurses’ caring behaviour when it was directed at more as compared to less distressed patients (HADS, CPI). Nurses reported providing more care labelled as Comfort and Anticipates to patients they rated as highly troubled by their emotional problem (CPI) than they did to less troubled patients, but this was not substantiated in the patients’ ratings.

Table 6. Correlations between patient and nurse ratings of implemented care

<table>
<thead>
<tr>
<th>Individually planned nursing interventions a</th>
<th>Patients mean (SD)</th>
<th>Nurses mean (SD)</th>
<th>(r)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>(n=54)</td>
<td>4.72 (2.65)</td>
<td>4.50 (1.85)</td>
<td>0.17</td>
<td>0.227</td>
</tr>
<tr>
<td>CARE-How Often a</td>
<td>(n=69)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Monitors and follows through</td>
<td>4.87 (1.12)</td>
<td>5.18 (1.22)</td>
<td>0.21</td>
<td>0.088</td>
</tr>
<tr>
<td>Accessible</td>
<td>4.64 (1.36)</td>
<td>4.34 (1.26)</td>
<td>0.49</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Comforts</td>
<td>3.86 (1.10)</td>
<td>3.75 (0.96)</td>
<td>0.35</td>
<td>0.003</td>
</tr>
<tr>
<td>Trusting relationship</td>
<td>3.27 (1.04)</td>
<td>3.55 (0.95)</td>
<td>0.29</td>
<td>0.015</td>
</tr>
<tr>
<td>Explains and facilitates</td>
<td>2.98 (1.57)</td>
<td>3.07 (1.70)</td>
<td>0.36</td>
<td>0.003</td>
</tr>
<tr>
<td>Anticipates</td>
<td>1.91 (1.27)</td>
<td>1.99 (1.32)</td>
<td>0.15</td>
<td>0.212</td>
</tr>
</tbody>
</table>

a min-max = 0-7.
Study III

Nurse overestimation of cancer patients’ problems did not appear to be of importance to patients’ satisfaction with care. However, when nurses failed to identify individual patients’ level of depressive problems (i.e., underestimated patients’ HADS), patients were significantly less satisfied with the care they received from their matched nurse (NSC) (Table 7). It is important to note that this subgroup of “nurse underestimation” included patients both self-rated as non-cases (n=5) as well as doubtful (n=4) and clinical cases (n=6) of depression, according to recommended cut-off scores. In addition, patients’ self-reported levels of anxiety and depression (HADS) on the day of arrival at the ward were of importance for subsequently rated satisfaction with care from the nurses as a group (CASC); patients with higher levels of anxiety and depression were significantly less satisfied with some aspects of care (e.g., nurses’ Availability). Analysis of the open questions based on patients’ statements concerning their experiences of received care resulted in four subcategories: Overall impression of care, Staffs’ personal qualities, Availability in care and Physical environment and were grouped into three categories – Satisfied needs and expectations, Unsatisfied needs and expectations and Desirable improvements in care (Table 8). Although both patients’ ratings and patients’ experiences of received care indicated a high degree of satisfaction, patients also expressed several negative experiences with care. They would have preferred a more honest, involved and available and less stressed staff. They also desired changes in information provision and improvements in the physical environment.
Table 7. Differences in satisfaction with received (NSC)/provided (PSC) care between subgroups based on patient-nurse dis/agreement

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Nurse underestimation (n)</th>
<th>Nurse overestimation (n)</th>
<th>Agreement (n)</th>
<th>Mean (SD)</th>
<th>*</th>
<th>p-value</th>
<th>Mean (SD)</th>
<th>*</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HADS Anxiety sub-scale</strong></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurse underestimation</td>
<td>(11)</td>
<td>(40)</td>
<td>(28)</td>
<td>38.3 (8.8)</td>
<td></td>
<td></td>
<td>33.7 (5.7)</td>
<td></td>
<td>0.58</td>
</tr>
<tr>
<td>Agreement</td>
<td>(41)</td>
<td></td>
<td>(47)</td>
<td>36.6 (8.5)</td>
<td></td>
<td></td>
<td>33.2 (6.1)</td>
<td></td>
<td>7.02</td>
</tr>
<tr>
<td>Nurse overestimation</td>
<td>(13)</td>
<td>(47)</td>
<td>(19)</td>
<td>38.0 (5.0)</td>
<td></td>
<td>0.58</td>
<td>38.0 (7.4)</td>
<td></td>
<td>0.030*</td>
</tr>
<tr>
<td><strong>Depression sub-scale</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurse underestimation</td>
<td>(13)</td>
<td>(47)</td>
<td>(19)</td>
<td>32.1 (8.7)</td>
<td></td>
<td></td>
<td>32.5 (6.0)</td>
<td></td>
<td>2.95</td>
</tr>
<tr>
<td>Agreement</td>
<td>(14)</td>
<td>(47)</td>
<td>(18)</td>
<td>38.0 (7.4)</td>
<td></td>
<td></td>
<td>32.3 (6.1)</td>
<td></td>
<td>0.05</td>
</tr>
<tr>
<td>Nurse overestimation</td>
<td>(35)</td>
<td>(43)</td>
<td>(3)</td>
<td>39.5 (5.7)</td>
<td></td>
<td>7.02</td>
<td>39.5 (5.7)</td>
<td></td>
<td>0.23</td>
</tr>
<tr>
<td><strong>CBI</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurse underestimation</td>
<td>(35)</td>
<td>(33)</td>
<td>(3)</td>
<td>39.2 (5.8)</td>
<td></td>
<td></td>
<td>31.8 (9.1)</td>
<td></td>
<td>4.86</td>
</tr>
<tr>
<td>Agreement</td>
<td>(41)</td>
<td>(43)</td>
<td>(3)</td>
<td>36.3 (8.4)</td>
<td></td>
<td></td>
<td>36.2 (2.4)</td>
<td></td>
<td>0.08</td>
</tr>
<tr>
<td>Nurse overestimation</td>
<td>(3)</td>
<td>(33)</td>
<td>(4)</td>
<td>30.7 (9.1)</td>
<td></td>
<td>4.86</td>
<td>30.7 (9.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>FACIT-Sp</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurse underestimation</td>
<td>(32)</td>
<td>(32)</td>
<td>(4)</td>
<td>39.2 (5.3)</td>
<td></td>
<td></td>
<td>32.2 (6.1)</td>
<td></td>
<td>1.05</td>
</tr>
<tr>
<td>Agreement</td>
<td>(43)</td>
<td>(43)</td>
<td>(4)</td>
<td>37.0 (8.0)</td>
<td></td>
<td></td>
<td>32.8 (6.4)</td>
<td></td>
<td>0.59</td>
</tr>
<tr>
<td>Nurse overestimation</td>
<td>(4)</td>
<td>(4)</td>
<td>(4)</td>
<td>31.8 (15.5)</td>
<td></td>
<td></td>
<td>28.7 (6.2)</td>
<td></td>
<td>1.81</td>
</tr>
</tbody>
</table>

Nurse underestimation = differences between nurse and patient ratings > minus 15; Agreement = differences between nurse and patient ratings =15 to 15; Nurse overestimation = differences between nurse and patient ratings > 15; Min-max, NSC and PSC = 0-48; * = Kruskal-Wallis test; *= significant differences between the subgroups Nurse underestimation and Agreement and between the subgroups Nurse underestimation and Nurse overestimation.
Table 8. Patients’ descriptions of received care

<table>
<thead>
<tr>
<th>Subcategories</th>
<th>Satisfied needs and expectations</th>
<th>Unsatisfied needs and expectations</th>
<th>Desirable improvements in care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Overall impression of care</strong></td>
<td>Functional, good, excellent and terrific care. (19)</td>
<td>Expectations of continuity in care not confirmed. (1)</td>
<td>Meeting fewer staff. Less expensive health care. (2)</td>
</tr>
<tr>
<td><strong>Staffs’ personal qualities</strong></td>
<td>Pleasant, social, thoughtful and accommodating. Listening, having knowledge and information skills. (30)</td>
<td>Acting fawning and uncertain, demonstrating lack of information skills. (7)</td>
<td>A more honest and involved staff. A staff that have answers to questions. A staff with better knowledge of individual patients’ problems and needs.</td>
</tr>
<tr>
<td><strong>Availability in care</strong></td>
<td>Available care and an attentive staff who promptly answer calls. (6)</td>
<td>Unavailable care and staff. (5)</td>
<td>A less stressed and more relaxed staff and staff members who remain with the patient for at least five minutes. Less waiting-time. (10)</td>
</tr>
<tr>
<td><strong>Physical environment</strong></td>
<td>Peace and quiet at the ward. (2)</td>
<td>Disturbing environment. (2)</td>
<td>Possibilities for peace and quiet on the ward. Place patients together on the basis of individual needs. A more aesthetic interior at the ward. Improvements in cleaning and hygiene. (12)</td>
</tr>
</tbody>
</table>

(XX) = number of patients who made statements categorized as the specific subcategory

Study IV

Initial nurse-patient agreement concerning individual cancer patients’ situation did not appear to be of importance to nurses’ subsequent satisfaction with provided care directed at specific patients (PSC) (Table 7). However, nurses who were in consistent agreement with their matched patients concerning the patients’ situation differed from nurses who were in consistent disagreement in that they reported higher general work satisfaction (SWQ). Nurses in agreement were more satisfied with Psychosocial aspects of job satisfaction, Expectations and demands from superiors and co-workers and with Cooperation on the ward. Differences also emerged for Quality of care aspects; Nurses in who were in consistent
agreement with their matched patient reported significantly higher satisfaction scores for Nursing and medical care and Documentation than did nurses in consistent disagreement, indicating that nurses in agreement perceived they were providing higher quality in care. Higher satisfaction with provided care (PSC) as well as general work satisfaction (SWQ) was reported among nurses with extended experience of cancer care (≥2 years in the field) and among nurses who rated their workload during the study period to be as usual or lower than usual. Nurses with a higher education level (≥ Registered Nurse) only reported higher scores for general work satisfaction (SWQ).

Summary of findings
To summarize, at the group level a distinct pattern was shown in which nurses ascribed the patients with cancer more emotional distress (HADS), less resources to manage the situation (CBI) and a lower quality of life (FACIT-Sp) than the patients themselves reported. Concurrently, at the individual level, disagreement in the opposite direction was found; in a substantial percentage of cases, nurses had underestimated patients’ emotional distress and overestimated patients’ coping resources and quality of life. Thus, nurses and patients did partly agree on patients’ emotional distress, coping resources and quality of life. In short, the results revealed the following clinical importance of patient-nurse dis/agreement. With respect to how nurses act in relation to their perceptions of patients’ emotional distress patient-nurse dis/agreement did not seem to be important; with few exceptions, nurses did not report providing more care to patients with high levels of emotional distress. Further, nurses’ general tendency to overestimate cancer patients’ problems and suffering did not negatively influence patients’ satisfaction with received care; patients whose problems were overestimated by nurses were not less satisfied with their care. Instead disagreement in the opposite direction was shown to be of importance. Patients whose matched nurse underestimated their level of emotional distress (i.e., depression) were less satisfied with the care received from the specific nurse. Finally, nurse-patient agreement concerning cancer patients’ situation was not of importance to oncology nurses’ satisfaction with provided care.

Additional analyses
To improve the understanding of the findings of Study III and IV and to try to explain patients’ and nurses’ satisfaction with care, further tests were needed. A first step was to examine possible explanations, on the basis of
available data in two multiple regressions analyses. According to Tabachnick and Fidell (2001), a sample size five times higher than the number of independent variables in the equation (multiple regression) is a minimum but they recommend a ratio of 20. In the present thesis, the sample was limited and we had to accept the minimum recommendation.

Patients’ satisfaction with received care

First bivariate correlations (Pearson’s and Eta) were calculated between the hypothetical independent variables and the dependent variable (NSC). These independent variables were: patients’ age, gender, aim of treatment, earlier stay at the ward, time since diagnosis, HADS anxiety, HADS depression, total CBI, total FACIT-Sp, the patients’ ratings in CARE-How Often subscales as well as the nurses’ relative workload, education level, experience of cancer care and nurses’ satisfaction with provided care (PSC). Significant correlations were found for; HADS depression ($r=-0.35; \ p=0.003$), total CBI ($r=0.30; \ p=0.013$), total FACIT ($r=0.32; \ p=0.007$), for the CARE-How Often Subscales; Accessible ($r=0.48; \ p=<0.001$), Explains and facilitates ($r=0.30; \ p=0.014$), Comfort ($r=0.54; \ p=<0.001$), Anticipates ($r=0.27; \ p=0.026$), Trusting relationship ($r=0.56; \ p= <0.001$), Monitors ($r=0.46; \ p=<0.001$) as well as for nurses’ education level ($eta=0.25$).

This resulted in an equation with ten predictors. The first step was a multiple regression analysis (enter) with these predictors. The model was significant (Adjusted $R^2 = 0.44$), but only the predictor Trusting relationship had a significant Beta-coefficient. Therefore a stepwise multiple regression analysis was carried out. A model with two predictors was significant, occurrence of Trusting relationship and HADS depression explained 42% of the variance in NSC (Table 9). This means that patients were more satisfied with individual nurses’ care when they perceived that they more frequently received care rated as Trusting relationship and had lower levels of depression.

Table 9. *Model: Patients’ satisfaction with received care (NSC)*

<table>
<thead>
<tr>
<th>Model and predictors</th>
<th>Unstandardized Beta</th>
<th>Standardized Beta</th>
<th>t-value</th>
<th>p-value</th>
<th>VIF</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adjusted $R^2 = 0.419$</td>
<td>Trusting relationship</td>
<td>3.803</td>
<td>0.561</td>
<td>6.065</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td>HADS depression</td>
<td>-0.605</td>
<td>-0.349</td>
<td>-3.779</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

Dependent variable
NSC, min-max=0-48

42
Nurses’ satisfaction with provided care

We started again by calculating bivariate correlations (Pearson’s and Eta) between the dependent variable (PSC) and the hypothetical independent variables. These independent variables were: the nurses’ relative workload, education level and experience of cancer care, nurses’ ratings of patients’ HADS anxiety, HADS depression, total CBI, total FACIT-Sp, how troublesome the nurses rated the patients’ emotional problem, the nurses’ rating of CARE-How Often subscales and patients’ satisfaction with care (NSC). Significant correlations were found for Relative workload (r=-0.37; p=0.001), Experience of cancer care (eta=0.23, eta²=0.05), How troublesome the nurse rated patients’ emotional problem (r=0.37; p=0.004), as well as the CARE-How Often subscales: Explains and facilitates (r=0.32; p=0.007), Comfort (r=0.31; p=0.010), Anticipates (r=0.26; p=0.032), Trusting relationship (r=0.42; p=<0.001) and Monitors (r=0.40; p=0.001).

This resulted in an equation with eight predictors. In the same manner as with patients’ satisfaction with care, we started with a multiple regression analysis (enter) with all eight predictors. The model was significant, Adjusted R² = 0.48, but only the predictors Relative workload, Experience of cancer care, Troublesome emotional problem and Trusting relationship had significant Beta-coefficients. Therefore a stepwise multiple regression analysis was carried out. The significant model with these four predictors explained 51% of the variance in PSC (Table 10). This means that oncology nurses were more satisfied with provided care to a specific patient if they perceived that they more frequently had provided care rated as Trusting relationship, had a lower workload than usual, had extended experience of cancer care and perceived that the patient was highly troubled by an emotional problem.

Table 10. Model: Nurses’ satisfaction with provided care

<table>
<thead>
<tr>
<th>Model and predictors</th>
<th>Unstandardized Beta</th>
<th>Standardized Beta</th>
<th>t-value</th>
<th>p-value</th>
<th>VIF</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. Adjusted R² = 0.513</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trusting relationship</td>
<td>1.990</td>
<td>0.308</td>
<td>3.114</td>
<td>0.003</td>
<td>1.147</td>
</tr>
<tr>
<td>Workload</td>
<td>-1.838</td>
<td>-0.358</td>
<td>-3.773</td>
<td>&lt;0.001</td>
<td>1.053</td>
</tr>
<tr>
<td>Experience of cancer</td>
<td>4.711</td>
<td>0.375</td>
<td>3.974</td>
<td>&lt;0.001</td>
<td>1.045</td>
</tr>
<tr>
<td>How troublesome</td>
<td>1.630</td>
<td>0.266</td>
<td>3.974</td>
<td>0.008</td>
<td>1.102</td>
</tr>
<tr>
<td>emotional problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dependent variable</td>
<td>PSC, min-max =0-48</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Discussion

The overall aim of the present thesis was to increase the knowledge and the understanding of dis/agreement between cancer patients and nurses regarding their perception of patients’ situation and of the importance of patient-nurse dis/agreement in clinical practice. In the following section, the results are first discussed in relation to the two actors, the patient with cancer and the nurse providing care, and then in relation to the framework of the caring relationship.

Insider perspective

The findings of the present thesis revealed a distinct pattern, in which patients’ perspective on their own situation was more positive and hopeful than that of nurses. In comparison to nurses’ perceptions, the patients ascribed themselves lower levels of anxiety and depression, stronger confidence in handling the situation of living with a cancer diagnosis and higher well-being. The findings showing that cancer patients at the group level rate lower levels of anxiety and depression and higher levels of quality of life than do nurses are in line with results from previous research (Bahrami et al., 2008; Lampic & Sjödén, 2000; Sneeuw et al., 2002; Sprangers & Aaronson, 1992; Steel et al., 2005).

Patients’ markedly more optimistic view of their resources for coping with cancer is, however, new knowledge (Table 5). The discrepancies between patients and nurses were moderate to large (ES >0.73) with regard to perceptions of patients’ ability to maintain activity and independence, accepting cancer and maintaining a positive attitude. It is evident in the literature that the insider perspective on being treated for and living with a diagnosis of cancer often entails an ongoing struggle to live in the present and maintain a normal daily life (Ekman et al., 2004; Kvåle, 2007; O'Baugh et al., 2003). Cancer patients’ strategies for living in the present have been shown to be inventive, creative and shifting (Salander, Bergenheim, & Henriksson, 1996) up until the end of life (Johansson, Axelsson, & Danielson, 2006; Sand, Olsson, & Strang, 2009). The obvious goal of these strategies is to maintain hope and to distance oneself somewhat from certain aspects of reality. As described in the Shifting Perspective Model of Chronic illness (Paterson, 2001; Thorne & Paterson, 1998), this distancing is not to
be confused with denial and non-acceptance, but instead entails strategies used to maintain some sort of normality. Patients’ high ratings in CBI, which indicate a strong confidence in managing to live with cancer, could be related to a need to mobilize resources to maintain normality.

It has also been argued that cancer patients’ quality of life ratings could be affected by measurement bias. A recent study by Westerman et al. (2008) showed that severely ill patients with cancer scored higher on questions regarding their physical and role functioning (scales in the EORTC-QLQ-C30\(^1\)) than what they actually could perform according to objective assessments of physical capacity. They found that the patients used various strategies to interpret the questions and present themselves as favourable and as having as few limitations as possible. Such strategies could be seen as coping efforts and as an additional explanation for the discrepancies seen between patients and nurses regarding more observable dimensions of quality of life. However, for the most parts, aspects of the patients’ situation, measured using HADS, CBI, FACIT-Sp, are not observable. How the patients choose to present themselves when responding to questionnaires (e.g., their confidence in coping with cancer) ought to concur with how they wish to present themselves to nurses in the admission interview.

Factors of clinical importance from the insider perspective

The fact that the patients held a more optimistic view of living with cancer than did the nurses who cared for them did not influence patients’ perceptions of the care they had received. From the perspective of patients, it did not seem to matter whether the nurse knew the patient well (was in agreement), or whether she/he overestimated the patient’s emotional problems and underestimated resources and well-being. However, one aspect of importance to patients’ satisfaction with received care was nurses’ ability to identify patients’ depressive problems. When the nurses failed to do so and underestimated patients’ level of depression in the admission interview, the patients were significantly less satisfied with the care they subsequently received. Thus, from the insider perspective, underestimated emotional problems were of clinical importance. Together, these findings contribute new knowledge to the concept of the patient-nurse relationship in cancer care, and somewhat contradict earlier findings stressing the importance for patients that nurses knowing them well (Dowling, 2008; Mok & Chiu, 2004).

The multiple regression analyses performed (Table 9) increased the ability to interpret the present findings. While nurse-patient agreement or disagreement regarding the patient’s situation did not contribute a great deal

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\(^1\) The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C30 (Aaronson et al., 1993)
to patients’ satisfaction with care, the occurrence of care distinguished by a trusting relationship did. This raises the question of what “knowing the patient well” actually means from the patients’ perspective. Perhaps components of nurses’ genuine interest in the patient, in getting to know the patient as an individual and putting the patient first, measured in the subscale Trusting relationship are more important than agreement regarding the patients’ situation. This finding is of special interest, as several studies have shown that patients with cancer prioritize and rank having a trusting relationship with nurses as less important to feeling cared for than other dimensions of nurses’ care described in the instrument CARE-Q, e.g., Accessible and Explain and facilitate (Chang, Lin, Chang, & Lin, 2005; von Essen & Sjödén, 2003; Larsson et al., 1998; Widmark-Petersson et al., 2000). The present findings revealed that a trusting relationship was the only dimension of care that contributed to satisfaction with care when patients with cancer evaluated occurrence of received care from a specific nurse.

Another aspect that contributed to patients’ satisfaction with received care from a specific nurse was level of depression (Table 10), a finding not detected in Study III where patients were divided into two groups according to recommended cut-off scores for the HADS (Bjelland et al., 2002; Zigmond & Snaith, 1983). The patients with high levels of depression and anxiety were also significantly less satisfied with some aspects of nurses’ (as a group) care (CASC) than were patients with low distress levels. Such relationships between cancer patients’ emotional distress and satisfaction with care have been shown in earlier studies (von Essen et al., 2002; Fröjd, 2007; Skarstein et al., 2002). One reasonable explanation of these findings is that patients with high levels of emotional distress had needs that they expected the individual nurse or the nurses to satisfy but that remained unmet. An alternative explanation for part of our findings is that depressed patients may have a generally negative view of life which also influences their perception of received care.

Although the patients’ ratings and experiences indicate a high degree of satisfaction, in the open questions patients also expressed several negative experiences of care (Table 8). The patients’ negative impressions of staff – such as uncertain, acting fawning, lacking of skills and not being available – could be seen as expressions of uncaring. This assumption is supported by the findings of Halldórsdóttir and Hamrin (1997). They found, when interviewing patients with cancer about caring versus uncaring, that nurses were perceived as uncaring when the patients perceived them as incompetent in some way. This included being indifferent to the patient as a person, as well as being indifferent to their own competence, and patients perceived such uncaring as an obstacle to their well-being and recovery.

It was evident in the patients’ open statements about their satisfaction with care that they experienced negative aspects in the physical environment and that they wanted improvements, e.g., in terms of aesthetics, cleaning and
Hygiene, peace and quite. One participant, a young man, guided the interviewer (GM) around the ward and pointed the limitations he saw in the physical environment (such as lack of room for privacy and no secluded corner for patients). He did not perceive the atmosphere at the ward and the visual art as forming a healing environment. Another participant stated that she took the elevator to the entrance floor every time she needed a toilet, because her toilet at the ward was so dirty. Similar statements were made by several patients. In light of cancer patients’ increased risk of infections the latter findings are of the utmost seriousness. According to Edvardsson et al. (2006), the physical environment is not merely a space for caring, it is an important part of cancer care and has been suggested to symbolize caring versus uncaring.

For getting a grasp on patients’ negative experience of care (i.e. expressions of dissatisfaction) the strategies used, which were inspired by Staniszewska and Henderson (2004), were successful. These strategies allowed patients to express negative experiences of care using narratives and indirectly by stating their wishes for different care, thus avoiding directly criticizing the care they had received.

Outsider perspective

The outsiders’ perceptions of the patients’ situation were more negative and pessimistic and thus confirm the phenomenon found in earlier research, i.e., nurses’ general tendency to ascribe patients with cancer more problems and suffering than the patients’ themselves report (Bahrami et al., 2008; Ewing et al., 2006; Horton, 2002; Lampic & Sjödén, 2000; Sneeuw et al., 2002; Sprangers & Aaronson, 1992; Steel et al., 2005). A striking finding was that the differences between the nurse and the patient regarding the patients’ situation were largest for areas that could be seen as patients’ resources (i.e., ES > 0.80 for three subscales of the CBI and for the FACIT-Sp subscale Social well-being) (Table 5). Thus, nurses caring for patients with cancer need to be aware of this phenomenon. An increased awareness of cancer patients’ more positive and optimistic view on living with cancer may reduce the potential risk of nurses verbally or nonverbally communicating their own more negative and pessimistic outlook to the patient. This, in turn, may reduce the potential risk that contact with health care system will lead to an undesired shift in perspective for patients with wellness-in-the-foreground. Paying more attention to patients’ resources and not only focusing on their illness, together with including patients’ self-experienced meaning of their situation, may help nurses to more accurately assess patients’ situation.

However, at the individual level, the contrary also was found (Table 5). In a substantial percentage of cases, nurses had underestimated patients’ emotional distress and overestimated their coping resources and quality of
life. Furthermore, in line with earlier research, we found that some nurses failed to identify clinical cases of anxiety and depression as indicated by patient ratings (von Essen et al., 1994; Lampic et al., 1996). Failure to identify individual patients’ problems could be seen as an ethical problem (Noddings, 2003). According to Noddings (2003), nurses have an ethical responsibility to act with open-minded responsiveness to patients’ needs. When nurses fail to identify such needs, patients are not acknowledged and are left alone in their suffering.

To our knowledge, no previous study has evaluated patient-nurse agreement regarding cancer patients’ spiritual well-being. In FACIT-Sp, spirituality is operationalized as a sense of meaning in one’s life, harmony, peacefulness and a sense of strength and comfort from one’s faith (Brady et al., 1999). Sweden is a secularized society in which spirituality is regarded as a private topic. A study by Ahmadi (2006) demonstrated that Swedish cancer patients did use spiritual coping primarily as a method to gain control over the situation. Swedish nurses have been reported to acknowledge the importance of spirituality for holistic care, but also to have difficulty defining the content of spiritually oriented care (Lundmark, 2006; Strang, Strang, & Ternestedt, 2002). The present results were therefore interesting and demonstrated that although nurses underestimated patients’ spiritual well-being, the percentage of patient-nurse agreement regarding the subscale Spiritual well-being was higher than for the subscales of quality of life Social and Emotional well-being.

At first glance, the findings (t-tests and correlations presented in Table 5) regarding the physical/functional dimensions of quality of life seem to support the assumption made by Farell (2005), namely that nurses focus on patients’ physical needs. But using several methods to analyse data from the pairs (differences, associations and agreement) helps to improve the understanding of the patient-nurse ratings. Regarding Physical and Functional well-being (i.e., visible and concrete domains), higher levels of agreement (expressed as, e.g., ICC, Kappa and correlations) have repeatedly been reported than for psychosocial domains (Brunelli et al., 1998; Sneeuw et al., 2002; Steel et al., 2005). In the present thesis, there was no significant patient-nurse group difference for Physical well-being, the standardized difference (ES) for Functional well-being was small and the correlations for both subscales were moderate. Interestingly, the percentages of patient-nurse agreement for these two subscales (in study-specific categories) were not substantially higher than those of the other subscales. Instead, a distinctive feature of the Physical and Functional well-being subscales was found to be a relatively high percentage of both nurse over- and underestimation. These results demonstrate that a non-significant group difference and a correlation above 0.50 may obscure patient-nurse disagreement when it is equally divided across over- and underestimation.
In the present thesis, nurse-patient agreement was measured directly after the admission interview, on the patients’ day of arrival at the ward. In two thirds of the cases, the patient and the nurse had never met before and this encounter was the starting point of the nurse-patient relationship. In such situations (after an admission interview of 20-30 minutes), some differences between nurses’ and patients’ ratings concerning the patient’s situation could be expected. At some occasions, nurses probably responded to items in the questionnaires without evidence from the short encounter with the patient, in other words they probably responded at random. However, only the findings regarding the observable Physical and Functional well-being supported that notion, indicating random patient-nurse disagreement in both directions (over- and underestimation). With respect to psycho-social variables, the present findings demonstrated systematic nurse-patient disagreement. One reasonable explanation for this systematic disagreement could be that nurses wished to safeguard the situation. Thus, when patients did not present manifest and visible problems in the admission interview, the nurses may have been afraid of inaccurately assessing the patients’ situation. The nurses did not want to present themselves as unable to identify patients’ problems when scoring in the questionnaires. In other words, nurses responded based on the motto “better safe than sorry”. Another probable explanation of the present systematic disagreement is that the nurses had an expectation of patients’ suffering based on their projection of how they themselves might experience the same situation (Lampic et al., 1996; Wright, 1983).

A final assumption is that the different perspectives of the insider and the outsider, owing to their different nature, lead to different perceptions of living with a life-threatening disease. Oncology nurses have in several studies described their relationships with cancer patients using strong emotional expressions, e.g., how they witness suffering, tragedy and a war against death (Corner, 2002; Ferrell & Coyle, 2008; Kendall, 2006, 2007). These studies also reveal that oncology nurses, who stand on the other side of the patients’ suffering, become emotionally involved and sometimes perceive this involvement as demanding. Standing on the other side of the cancer experience, and in contrast to the patient, not being directly exposed to the threat, also entail not being a part of the adaptation process (Lazarus & Folkman, 1984) that may help patients diagnosed with cancer manage to live in the present.

Factors of clinical importance from the outsider perspective

In contrast to expectation, initial patient-nurse dis/agreement was not shown to be of importance to oncology nurses’ subsequent evaluation of satisfaction with provided care directed to a specific patient. From the perspective of nurses, it did not seem to matter whether the nurse knew the patient well (i.e., was in agreement) or misjudged the patients’ situation (i.e.,
over- or underestimated). These findings to some degree contradict earlier research, based on nurse self-reports, which indicates that oncology nurses experience high work satisfaction when they report knowing the patient well (Mok & Chiu, 2004; Peteet et al., 1989). The approach in the above studies was qualitative and no previous studies have been found that investigated patient-nurse agreement using questionnaires and related the level of agreement to satisfaction with provided care.

Further, the present findings could not substantiate that nurses’ overestimation of cancer patients’ problems increased nurses’ workload and had detrimental consequences for their work satisfaction, as nurses assessed patients’ situation on an individual level and workload on a general level (including responsibility for other non-participating patients). However, in line with earlier research on job stress within cancer care (Barrett & Yates 2002; Sherman et al., 2006; Grunfeld et al., 2005), the present findings demonstrated that a heavy workload was negatively related to nurses’ satisfaction with care directed to a specific patient (PSC) and to nurses’ general work satisfaction (SWQ). Nurses who rated their workload higher than usual during the study period were less satisfied with psychosocial aspects of their work and with the nursing and medical care that they performed.

The multiple regressions analyses (Table 10) improved the understanding of nurses’ satisfaction with provided care. Not only a lower workload contributed to oncology nurses’ satisfaction with care, but also extended experience of cancer care and perceptions of having provided care characterized by a trusting relationship. Furthermore, nurses were more satisfied with provided care when they rated the patient as highly troubled by an emotional problem. One conceivable explanation for the latter finding is that in such cases, the task that has been reported to be a major source of work satisfaction among oncology nurses, i.e., alleviating patients’ suffering, is obvious (Grunfeld et al., 2005). In line with patients’ perceptions, only the dimension of care, Trusting relationship, contributed to nurses’ satisfaction with provided care. The notion of “knowing the patient” from the perspective of nurses is probably detected in this subscale, where items concern the nurse’s genuine interest in the patient, in helping the patient and in getting to know the patient as an individual. Radwin (1996) concluded that the concept “knowing the patient” involves recognizing patients as unique individuals. However, in earlier studies using the CARE-Q instrument, oncology nurses have not ranked this dimension of care as most important in cancer care (von Essen & Sjödén, 2003; Larsson et al., 1998; Widmark-Petersson et al., 2000), and while the subscales Anticipates and Comfort have been prioritized as most important for cancer patients feeling cared for, the subscale Trusting relationship has been given a lower rank. The present findings revealed that when individual nurses evaluated provided care to individual patients in terms of their own satisfaction, the
The occurrence of care labelled as trusting relationship was of importance. This finding thus supports earlier research showing that, from the nurses’ perspective, a trusting patient-nurse relationship is of importance in cancer care (Coffey, 2006; Dowling, 2008; Mok & Chiu, 2004).

The present thesis reveals that oncology nurses’ workload, experience of cancer care and education level need to be considered in cancer care. Experienced nurses (>2 years in the field) rated higher satisfaction with provided care (PSC) and with work (SWQ), indicating that amount of experience in cancer care may help nurses manage demands in daily work. It has been reported that a change in caregivers’ attitudes often occurs during the first two years of experience in cancer care, and this change is reported to involve a more confident and realistic view of helping and curing (Isikhan et al., 2004; Peteet et al., 1989). However, no evidence was found that experience of cancer care increased nurses’ ability to adequately assess patients’ situation i.e., “knowing the patient” (Radwin, 1996). Still nurses with an education level higher than registered nurse were more frequently in agreement with the patient concerning the patient’s situation.

Discussion within the framework of caring relationship

The chosen time point for the first data collection, the admission interview, could be seen as the starting point of a caring relationship. The data collected from the pairs directly after the admission interview demonstrated patients more positive and optimistic view of their situation. An additional potential explanation of these discrepancies could be related to the asymmetric relation between the patient and the nurse and to the nature of caring. As described previously, the first encounter lays the foundation for a caring relationship (Dowling, 2008; Kasén, 2002; Mok & Chiu, 2004). The goal of caring, to help the patient and alleviate his/her suffering, may trigger a motivation to identify problems. A patient who does not respond to the nurse’s invitation in the admission interview by presenting problems (Dowling, 2008; Kasén, 2002) may thereby obstruct or not facilitate the development of a caring relationship. Support for this notion was described by Kendall (2006), who indicated that “un-suffering” patients, who did not present problems made the nurses uncomfortable; nurses perceived this as patients questioning their role in offering help and their role as a nurse. However, one condition for accurately assessing a patients’ situation is having access to the patients’ thoughts and feelings (Heaven & Maguire, 1997). A study by Zaki, Bolger and Ochsner (2008) demonstrated that an individual’s capacity for affective empathy only predicts emphatic accuracy (agreement), while the other (in this case the patient) allows thoughts and feelings to be read.
Consequently, the goal of caring should trigger nurses’ motivation to alleviate identified problems. However, in the present thesis, no differences emerged in nurses’ caring behaviour when it was directed at patients the nurses rated as having low compared to high levels of anxiety and depression (HADS). This finding was surprising, especially because the nurses were also aware that their provided care was going to be evaluated and that it could be interpreted as showing that nurses predominantly provided standard care to patients irrespective of their assessment of individual patients’ problems, thus, challenging nurses’ statements concerning the importance of meeting every individual patient’s needs (Botti et al., 2006; Kendall, 2007). Further, these findings indicate lack of motivational displacement (Noddings, 2002), i.e., the nurses did not respond to their receptive attention that the patients had a high level of emotional distress. According to Noddings (2002), a caring encounter (in this case between the nurse and the patient) entails of three elements: 1) nurse’s attention and motivational displacement, 2) that the nurse responds to this attention and performs some act in order to help, and 3) that the nurse recognizes that the act of caring has occurred. The findings showed that nurses identified emotional problems among most patients and also planned individual nursing interventions that would alleviate these problems. However, nurses and patients did not perceive nurses’ subsequently implemented care in a similar manner. If the patient does not perceive a nursing intervention when it occurs, then the intervention has probably not served its particular purpose and may fail to achieve the desired outcome, i.e., to promote the patient’s health.

Moreover, patients and nurses did not evaluate the received/provided care in a similar manner. It could be expected that the patient’s level of satisfaction with received care should be reflected in the nurse’s rating of satisfaction with provided care. During the three-day relationship, the nurse had many opportunities to interpret signs and expressions of the patient’s satisfaction or dissatisfaction that may have affected her/his evaluation of provided care. However, that was not the case, there was no correlation between patients’ ratings of the NSC and nurses’ ratings of the PSC ($r=0.025$). Patients and nurses agreed about the importance of having a Trusting relationship. The findings demonstrated that occurrence of care labelled as Trusting relationship explained $\approx 30\%$ of the variance in patient-nurse ratings of satisfaction with care. Thus, the two actors, the patient and the nurse were shown to have somewhat different perceptions of the arena they shared. The aim was not to investigate caring relationships, but the findings indicate that after three consecutive days, not all relationships could be characterized as caring relationships.
Methodological considerations

Design and sample

The main strengths of the present studies are the prospective design of following individual matched pairs of patients and nurses, the high response rate and the low attrition rate, resulting in a large number of intact pairs after three consecutive days. Further, the instruments used to measure patient-nurse agreement had known psychometric properties, proxy versions of the instruments for nurses were used, there was a short time period between patient and nurse ratings (most often simultaneously), and selection of situations equal for all pairs (the admission interview and after three consecutive days).

One shortcoming of the design with individually matched pairs was the limited sample size, i.e. eighty-six patients were not approached because it was impossible to match them with a nurse. To avoid limiting the sample size further, 36 nurses were allowed to assess more than one patient at T1, despite the potential risk that nurses who participated twice might be in better agreement with their second matched patient. If they remembered questionnaire items, nurses could have specifically posed these questions in the admission interview with their next matched patient. In order to control for this risk, nurse ratings for their matched first and second patient were compared. For each subscale, the estimated nurse-patient difference (nurse score minus patient score) between nurse rating of patient 1 and nurse rating of patient 2 was compared (dependent t-tests), and no significant differences or strong correlations were found.

The procedure of collecting data via interview administration probably increased the response rate as well as decreased the attrition rate for patients. Especially on day three, a number of patients were affected by their illness and treatment, the consequence being that self-administration of the questionnaires would have been impossible. Despite their physical impairment, they were willing to participate in the study. In some cases, when the patients showed signs of “having had enough”, the interviewer (GM) acting on own initiative, limited the number of items to complete. This (together with other internal missing data) is the explanation for the somewhat different numbers of subjects in the scales/subscales.

Data collection

All but two instruments used have documented validity and reliability. No suitable instruments were found for measuring nurses’ care planning and for evaluating patients’ and nurses’ satisfaction with received and provided care, respectively, at the individual level. Therefore development of study-specific
instruments was needed (CPI and NSC/PSC). The CPI and NSC/PSC were piloted, but further tests of validity and reliability are required.

As presented in Table 4, the internal consistency for most instruments used was acceptable (> 0.70) for the patient sample, as well as for the nurse sample. However, two instruments and primarily the patient sample demonstrated lower Cronbach’s alpha values. The lower Cronbach’s alpha values with regard to the CARE-How Often could be due to the fact that participants were requested to assess care received during a relatively short time period (three days) and from an individual nurse. This was in contrast to the instructions used by von Essen and Sjödén (1995), who asked patients to assess received care during one week and from nurses as a group. Given the design of the present thesis, there was more frequent use of the response alternative “Not applicable” and thereby lower variability in the scales. Support for this notion is the low mean value for the subscale Anticipates 1.91 (Table 7), the subscale that also demonstrated the lowest internal consistency.

Internal consistency for the subscale Affective regulation (CBI) turned out to be low in the patient sample, contrary to the pilot study and earlier studies (Merluzzi & Martinez Sanchez, 1997a; Merluzzi et al., 2001). This subscale includes items on expressions of strong negative feelings, on the one hand, and the ability to withdraw from the situation through denial, escape and ignoring, on the other. The low Cronbach’s alpha could be a result of specific characteristics of the patient sample (one-half receiving palliative treatment), which differ from characteristics of the patients in the pilot study (mostly with curative treatment in an out-patient clinic) and earlier studies (Merluzzi & Martinez Sanchez, 1997a; Merluzzi et al., 2001). Furthermore, the low internal consistency of the subscale Affective regulation could be due to shortcomings in the translation. The Swedish version of the CBI has not been sufficiently validated and further testing is necessary.

One additional potential shortcoming needs to be discussed. Nurses’ caring behaviour (CARE-How Often) was shown to differ somewhat between patients that nurses rated as highly troubled by emotional problems and patients nurses rated as less troubled (CPI). Furthermore, nurses’ rating of how troublesome the emotional problem was for the patient (CPI) was a predictor of nurses’ satisfaction with provided care (PSC). It is surprising that nurses’ rating of patients’ HADS did not show the same pattern. One interpretation of this finding is that the HADS, which is more abstract, is not suitable for use in its proxy-version directly after the admission interview.

Data analysis

One strength of Study I was the combination of several statistical methods used for analysis of data from the matched pairs (Jacobsen et al., 1991). This
approach improved the understanding of patient-nurse dis/agreement concerning the patient’s situation. The present operationalization of patient-nurse agreement in new categorical variables (Overestimation, Agreement and Underestimation) that was used could be regarded as a limitation as the category boundaries were neither grounded in theory nor validated. However, the categorization in the present thesis is in line with the interpretation of significant and meaningful changes in quality of life scores for individual cancer patients (Osoba, 2002; Osoba, Rodrigues, Myles, Zee, & Pater, 1998). According to Osoba (2002), changes larger than 5 on scales of 1-100 are perceptible to individuals, but he suggested changes larger than 10 as a rational approach to interpreting clinically significant changes in quality of life scores. Thus, the principles used in the present thesis to consider patient-nurse differences larger than ±15 as overestimation and underestimation would seem to be reasonable.

The systematic but arbitrary principles used to categorize agreement were also used to divide the sample into subgroups. Further, parts of the main findings in the present thesis are based on comparisons between these subgroups. Hence there is a need to further discuss the principle of grouping the pairs into subgroups. When the patients did not present problems, e.g., rated very low levels of HADS, it was impossible for the nurse to underestimate the patients HADS (floor effect), and these pairs could not be assigned to the subgroup Underestimation. Similarly, when the patients gave very high ratings, the ceiling effect entailed that such pairs could not be assigned to the subgroup Overestimation. To control for methodological bias, all pairs subject to ceiling or floor effect (in HADS, CBI, FACIT-Sp) were eliminated and the analyses were re-run. The results showed that the findings presented in Study III and IV (Table 7) remained and thus are valid.

The indication that only one dimension of care, occurrence of a Trusting relationship, predicted patients’ and nurses’ satisfaction with care needs to be validated in future research. The correlation ($r$) between the CARE-How Often subscale Trusting relationship and the other subscales, except Accessible, varied between 0.61-0.68 in nurse ratings (VIF, variance inflation factor < 2.8), and between 0.34-0.76 in patient ratings (VIF < 3.2). Thus it is possible that the other CARE-How Often subscales would also have predicted satisfaction with care if the subscale Trusting relationship had been removed from the regressions.

A significance level of 0.05 was chosen for all tests, despite a large number of statistical analyses and the risk of mass-significance. However, considering the opportunity to explore unknown consequences of patient-nurse dis/agreement in clinical practice, this risk was preferred of the risk of committing a type II error.
Concluding remarks and clinical implications

The quantitative approach used in the present thesis offers new insight into elusive constructs and phenomena most often investigated using qualitative approaches. The rationale was the need to explore the consequences of patient-nurse dis/agreement for clinical practice. The overall findings indicate that initial patient-nurse agreement concerning patients’ emotional distress, coping resources and quality of life is of little significance when patients and nurses subsequently evaluate received and provided care. Further, nurses’ general tendency to overestimate patients’ problems has minor consequences for nurses’ subsequently implemented care, and no consequences for patients’ and nurses’ satisfaction with received/provided care. In contrast, nurses’ underestimation of patients’ depressive problems is of importance when patients evaluate received care. Patients cared for by nurses who underestimated their level of depression were less satisfied with those nurses’ care than were remaining patients. Thus, nurses caring for patients with cancer need to improve their ability to assess patients’ emotional distress, and especially their ability to interpret the signs and symptoms of depression. One basic prerequisite for this is to gain access to patients’ thoughts and feelings, something that could be facilitated by having enough time with the individual patient and the opportunity to perform the admission interview in a secluded room. Further, to ensure individualized care, nurses must closely validate the accuracy of their assessments of patients’ problems and needs and their planned strategies for alleviating patients’ problems in collaboration with the patients.

Although the rationale was to explore consequences of patient-nurse dis/agreement, the findings also improved the understanding of trusting patient-nurse relationships in cancer care. The more frequently the nurse had implemented care characterized by a trusting relationship, the higher patients’ and nurses’ satisfaction with received/provided care. An important aspect concerning the frequency of received/provided care must be that there is enough time available for nurses to provide care. The patients in the present thesis reported experiencing a sometimes stressed staff with lack of availability, which could reasonably be related to a heavy workload. However, it must be taken into account that nurses on some occasions prioritized their time with patients based on incorrect assessments. If oncology nurses were able to more accurately assess their patients’ situation, they could also prioritize their time with the patients based on patients’ actual needs and thereby perhaps increase the frequency of care that is satisfying to both patients and nurses.

The present thesis increased the knowledge of aspects of importance for nurses’ perceptions of performing satisfying work. Seen as indicators of quality of care, these aspects (experience of cancer care, perceived workload and education level) need to be addressed. Less experienced nurses’ (novice
and advanced beginners’) lower satisfaction with provided care and lower general work satisfaction could be the result of high work demands and require attention. In light of oncology nurses’ demanding work and increased risk for work-related stress, the negative effect of a heavy workload on nurses’ perception of performing satisfying work requires more attention. Finally, a high education level seems to have a positive effect on oncology nurses’ ability to assess patients’ situation as well as on their work satisfaction. When nursing staff are recruited to oncology settings, both the mix of inexperienced/experienced nurses and the differences in education level need to be taken into consideration.
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Ett känt fenomen är att sjuksköterskor, liksom annan vårdpersonal, har en tendens att tillskriva patienter med cancer mer problem och ett större lidande än vad patienterna själva rapporterar att de har. Det övertygande syftet med avhandlingsarbetet var därför att få ökade kunskaper om och förståelse för detta fenomen samt för den kliniska betydelsen av att patienter och sjuksköterskor är överens kontra inte överens om hur patienten mår.


I delarbete I (n=90 par) undersöktes överensstämmelsen mellan patienter och vårdansvariga sjuksköterskor rörande patientens oro och nedstämdhet, copingresurser och livskvalitet. Resultatet visade ett tydligt mönster där sjuksköterskorna överskattade patienternas oro och nedstämdhet samt underskattade patienternas copingresurser och livskvalitet. Men trots en överskattning av patienternas oro och nedstämdhet på gruppnivå identifierades också flera fall där sjuksköterskor tydligt underskattat individuella patienters höga självskattade grad av oro och nedstämdhet. I delarbete II (n=81 par) var syftet att undersöka sjuksköterskornas vårdplanering och genomförda vård i relation till den bedömning de gjort av patienternas emotionella besvär. Resultatet visade att sjuksköterskornas genomförda vård inte skilde sig nämnvärt åt mellan patienter de bedömde ha mer respektive mindre besvärande emotionella problem eller mellan patienter med låg respektive hög grad av oro och nedstämdhet.
Sjuksköterskor och patienter bedömde inte heller förekomsten av den genomförda vården på liknande sätt. I delarbete III (n=82 par) undersökt om initial överensstämmelse/diskrepanse inom patient-sjuksköterskeparet rörande patientens situation (oro och nedstämdhet, copingresurser och livskvalitet) hade konsekvenser för patienters vårdtillfredsställelse. Resultatet visade att varken överensstämmelse eller sjuksköterskors överskattning av patienternas problem var av betydelse för patienters tillfredsställelse med den vård de erhållit av en specifik sjuksköterska. Däremot var patienter som vårdades av en sjuksköterska som underskattade deras grad av nedstämdhet mindre tillfredsställda med sin vård än övriga patienter. I delarbete IV undersökte om initial överensstämmelse/diskrepanse inom patient-sjuksköterskeparet (n=81 par) rörande patientens situation (oro och nedstämdhet, copingresurser och livskvalitet) hade konsekvenser för sjuksköterskors tillfredsställelse med den vård de gav. Resultatet visade att varken överensstämmelse eller sjuksköterskors överskattning/underskattning av patienternas problem var av betydelse för sjuksköterskors tillfredsställelse med den vård de gav en specifik patient.

För att få en ökad förståelse för resultaten i delarbete III och IV genomfördes ytterligare analyser. Dessa visade att patienterna var mer tillfredsställda med den vård de fått av en specifik sjuksköterska om de hade lägre självskattad nivå av nedstämdhet samt rapporterade att de i högre frekvens fått vård som kännetecknades av en förtroendefull relation mellan patienten och sjuksköterskan. Sjuksköterskorna var mer tillfredsställda med den vård de gav en specifik patient om de hade längre erfarenhet av arbete inom cancervård, lägre arbetsbelastning under studieperioden, och vid ankomstsamtalet bedömt att patienten hade besvärande emotionella problem samt rapporterade att de i högre frekvens tillhandahållit vård kännetecknad av en förtroendefull relation mellan patienten och sjuksköterskan.

Sammanfattningsvis visar detta avhandlingsarbete att sjuksköterskors tendens att överskatta patienters problem och lidande inte verkar ha någon betydelse för (1) hur sjuksköterskor agerar utifrån den bedömning de gör av patienters situation samt för (2) patienters och (3) sjuksköterskors tillfredsställelse med den vård som tillhandahållits. Däremot förefaller det vara viktigt för patienters vårdtillfredsställelse att sjuksköterskor har förmåga att identifiera patienters nedstämdhet.
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