Improving communication in cancer care

A quasi-experimental study testing the effects of an interactive tailored patient assessment on communication between cancer patients and physicians and nurses

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Development of the current study

When Cornelia Ruland and her research team conducted a randomized controlled trial (RCT) to test the effects that an electronic symptom assessment tool had on patient outcomes and documented care, I was working at one of the participating wards and got interested in this new technology. The results from this RCT showed significant positive effects, and consequently the participating wards wanted to implement this symptom assessment tool into their daily routines. This provided an excellent opportunity to investigate further what exactly caused the positive impact on patient outcomes, particularly what impact the utilization would have on the communication between the patient and the clinician. A new study was designed, which resulted in this thesis.

This thesis has been made possible by the collaboration of three parties. First and foremost the Center for Shared Decision Making and Nursing Research at Oslo University Hospital, Rikshospitalet, who developed, tested, and implemented the Choice ITPA, and Cornelia Ruland, who has been the principle investigator for this study and also my main supervisor from January 1st 2008 until May 31st 2010 and my co-supervisor for the rest of the period. Secondly, Arnstein Finset at the Department of Behavioral Sciences in Medicine, Institute of Basic Medical Sciences at the University of Oslo, was brought into this study due to his expertise in the field of communication in health care. He has contributed in the analysis and was my co-supervisor from January 1st 2008 until May 31st 2010, and my main supervisor from June 1st 2010 until the thesis was completed in December 2011. Lastly, the Research Council of Norway that has funded this study, grant # 177500/V50.
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Thank You!
List of papers


4. Finset, A., Heyn, L., Ruland, C.M. Responses of physicians and nurses to patients’ emotional cues and concerns in cancer care consultations. J Gen Intern Med (submitted)

5. Heyn, L., Finset, A., Eide, H., Ruland, C.M. Patient-clinician communication assisted by an interactive tailored symptom assessment: differences and similarities in nurses’ and physicians’ communication patterns. Supportive Care in Cancer (short communication, submitted)
1 Introduction

The focus of this thesis is patient-clinician communication in cancer care and how new technology potentially can aid patients as well as clinicians, such as physicians and nurses, with communication about symptoms and problems related to living with cancer. This study was conducted to provide insight into the field of patient-clinician communication with and without new technology to support communication about symptoms and problems between cancer patients and physicians and nurses.

As a novice nurse, I had an experience with a young cancer patient that early in my career made me realize the importance we as clinicians have on cancer patients’ lives. This patient was a young married man, who just recently had become a father when he was admitted with lymphoma. It was a type of cancer that he luckily had good odds of recovering from. The ward where this took place was a surgical ward, and the surgery he was admitted for was considered a standard procedure with good prognosis by the surgeons. Because of the good prognosis, no one expected any anxiety from this patient; neither did they take his fears seriously when confronted with them. This patient was told that his prognosis was good and that he therefore had nothing to worry about. When the patient described his concerns to me, about the procedure, the prognosis, and about not being taken seriously, he described it in a way that was so powerful that I confronted the head of the department and asked him to talk to this frustrated young man. As a result of this, the patient was able to discuss all his concerns with the physician and ended up being transferred to a hospital that specializes in cancer treatment. This was initially what he wanted, but he was just told that there was no need for this and that his prognosis was good. Being a nurse, I am not sure if this decision was medically the right one, but I do know that it was important for that man to be taken seriously and to allow him to discuss his fears about his baby growing up without his dad. I know that he felt more at peace with this outcome, and it made me realize how important it is to acknowledge the patient’s perspective in order to provide the best care possible. Clinicians
have a habit of telling patients not to worry, but the reality is that cancer patients will constantly worry. We need to realize that and communicate on their premises.

What I learned from this experience symbolizes this thesis. I learned what impact it had on my patient to listen and acknowledge his concerns and to incorporate that into the care I planned for him. This thesis is about the importance of eliciting the patient’s perspective and to demonstrate how to do so by using new technology.

1.1 Communication in health care

Communication is defined as a ‘process in which a message containing information is transferred’ (1) and has been described as a reciprocal process where messages are sent and received, either verbally or non-verbally (2). The main concepts of the communication process have been illustrated by Schramm (Figure 1). When a message is sent (encoded), the receiver must decode the message and communicate back that the message was received correctly (3). Translated to the patient-clinician relationship, this means that both the patient and the clinician participate in the encounter, and both function as information-givers as well as information-receivers (4). Patients are the experts on their own symptoms, concerns, and what matters most to them (5) and it is important that they share this information with their clinician. Patients are therefore important information-givers in that they need to provide sufficient information for the clinician to determine the right diagnosis, to find the right treatment, and to provide best care. On the other hand, patients need to receive sufficient information in order to participate in decision making and to have all their needs met (6). Consultations are often restricted in time due to clinicians’ busy schedules, meaning that the essence of the patients’ problems must be found rather quickly (4). This poses an extra challenge to the communication process.
Figure 1 Schramm’s model of communication

It has been documented that patients rank communication ability as one of the most important features of a clinician (6). Patients generally want more information than they are provided with (7;8), and lack of sufficient information can potentially cause harm to patients (7). The main reason patients reported why they considered communication skills to be such an important feature of their clinicians was that they valued the sense of being listened to and the feeling of being understood. This was regarded as more important than to be part of the decision making process (6). Even if patients want more information, several studies have found that they are generally satisfied with information from clinicians (9-11). However, when thoroughly examining the different aspects of the information given, a more nuanced pattern emerged. Mallinger and colleagues (9) found that patients were very satisfied with information about treatment but only moderately satisfied with information regarding long-term physical, psychological, and social implications. Similar results were also found in a study by Moret and colleagues (10). This study found that 20% of patients neither were satisfied with information given on risk-benefit ratio of treatment, nor with possible side effects (10). These findings are imperative not only because they result from a large sample (N=1246), but also because they demonstrate discrepancies between patients’ and clinicians’
perception. One third of the physicians and nurses (N=835; n=302, n=533 respectively) reported that they explained the risk and benefits of assessment, procedures, and treatment verbally and accompanied it with written information to the patient, yet many patients did not perceive this information as sufficient. This shows that patients can be left with unmet needs and unanswered questions without clinicians even knowing.

It has been documented that communication is a clinical skill that clinicians need to be taught (12), but also that lack of communication skills and training among health care clinicians is common (13). In Norway, communication courses have been a part of the curriculum for medical students for the last ten years. For nursing students, there are currently existing national guidelines on including communication into the curriculum, but different nursing schools have different practices (14). Despite existing knowledge that communication skills need to be taught and repeated (15), the only specialization that includes a compulsory communication course is oncology. Other European countries, such as the UK, have integrated communication skills training into the undergraduate and postgraduate education of all health care professionals (15). Lack of communication training causes poor skills and low confidence, particularly when discussing sensitive topics (16;17).

1.2 Communication with cancer patients
Cancer research has previously focused on developing new and better treatments and consequently, on managing symptoms that follow from this treatment. The major effort that has been made to develop new treatments has resulted in cancer becoming a chronic disease. As a result, a growing population of cancer survivors emerges, and we are only scratching the surface regarding long-term effects and consequences of the treatment they have received. As a result of the increasing population of cancer patients and post-cancer patients, the type and quality of communication between clinicians and cancer patients will impact a large number of people.
Cancer patients, either in treatment or survivors, compose a vulnerable population with increased information needs (18;19). They depend heavily on their clinicians in regard to coping with physical, emotional, and social burdens, which affect their quality of life. Cancer patients experience multiple symptoms during treatment and rehabilitation, physical, psychosocial, and emotional. What distinguishes cancer symptoms from other diseases is first and foremost the constant uncertainty of the outcome of the treatment. Even when the treatment is successful, there is a constant fear of relapse (20). A recent review concluded that recurrent disease was one of the main concerns for cancer patients in follow-up care, and that the more recently they completed treatment, the more concerned they were (20). This is consistent with a recent study by Grimsbø and colleagues (21), where cancer patients described a constant fear of relapse or spread of the disease. Cancer patients typically have a long period where they are under treatment and control, and consequently the care involves a number of different clinicians and institutions (specialist hospital, general hospital, GP, etc). This poses another challenge to the communication with cancer patients, as they meet new clinicians numerous times (22).

Although clinicians have reported communication to be a challenging task, it is the foundation of caring for cancer patients (22). These patients have large needs for information, but the information must also be given repeatedly, as a crisis like cancer is likely to block the ability to receive information. Information must be given thoroughly and needs to be repeated in order for patients to avoid unnecessary worries. It is a common mistake among clinicians that cancer patients need to be protected from “worst-case scenario”-information. Studies report that cancer patients desire more information than they receive, and also that the majority want detailed information (19;23). However, as every cancer patient might have individual information preferences, clinicians need to evaluate this first. Cancer patients require both honest medical and treatment related information as well as emotional support.
Previous research has demonstrated that patients cope better with their disease when they receive open and honest communication from their clinicians (2;24). Therefore, the challenge for clinicians is to elicit each patient’s information need and to provide tailored information in a timely manner.

1.3 Theoretical Framework

The theoretical framework for this study is based on Hildegard Peplau’s theory on interpersonal relations (25). This theory was originally developed based on communication between nurses and their patients, as Peplau herself was a nurse. However, the theory describes how and why to establish an interpersonal relationship with patients, which applies just as much to physicians as to nurses. The relationship between patients and clinicians are primarily established through communication. Communication is essential in all human interaction, and one of the first to acknowledge this in health care was Hildegard Peplau (26). When no communication exists, the development of relationships between individuals cannot occur (27). Peplau described in her theory that the relationship between clinicians and patients is a fundamental part in order to provide the best care possible; it is actually one of the core features of nursing (28). Peplau emphasized that communication has an expanded definition in health care. In addition to giving and receiving information, communication between clinicians and patients also include transmission of feelings (2).

According to Peplau, the relationship between a patient and a clinician is developed within three phases:

- The orientation phase, where the patient and the clinician begin establishing a relationship.
- The working phase, where the patient and clinician jointly identify the patients’ problems, ensure that the patient understands the consequences of these problems, and prepare a plan for solving the problems.
- The termination phase, where the work is summarized and closure is prepared.
In her original work from 1952, Peplau described four stages; orientation, identification, exploitation, and resolution. In her later work from 1997 (29) she combined the two phases identification and exploitation into the working phase. Even if the phases are described separately, Peplau emphasized that they are overlapping. During the orientation phase, the interpersonal relationship between the patient and the clinician emerges. One major barrier to overcome is the fact that the patient has a problem or a need and seeks assistance from the clinician, yet they are strangers at the first meeting. As the clinicians are the professionals, it is their responsibility to initiate the establishment of the relationship. The goal of the orientation phase is to come to a mutual understanding of the problem or need the patient initially sought assistance about. According to Peplau, the orientation stage of the patient-clinician relation will influence anxiety either positively or negatively (25). When patients have unmet needs, they face the possibility of untreated symptoms and deterioration of psychological state. Peplau describes that psychobiological experiences will influence how patients function, resulting in either constructive or destructive behavior. In addition to the tension that stress creates, it also releases an energy that can lead to either constructive or destructive behavior (30). Constructive behavior will provide patients with a sense of security, whereas destructive behavior will result in anxiety (25). For this reason it is crucial that clinicians realize the importance of the orientation phase. It is the clinician’s role to recognize the source of the patient’s tension from stress or from unmet needs, and to make sure that the energy released from that tension becomes positive by helping the patient to accept their disease and teach them new patterns of behavior that facilitate coping.

Peplau described her theory on interpersonal relations as early as in 1952. Although she never used the world patient centered, her descriptions of how to establish an interpersonal relationship is comparable to patient centeredness, which today is widely studied and considered to be the foundation of quality care (31). In 1977, George Engel
presented the biopsychosocial model, in which he attempted to incorporate the missing dimensions of the biomedical model (32). Consistent with this model and Peplau’s theory, this study includes investigations of the relational and emotional aspects of the patient-clinician communication.

1.4 Patient centered communication

Numerous concepts with the basis ‘patient centered’ have been defined and redefined over the past four decades, such as patient centeredness, patient centered communication, patient centered care, and patient centered medicine / nursing. The definitions have been slightly altered during this period, and although the concepts are different, they are related and come from the same roots. In 1969, Balint defined patient centered medicine as ‘understanding each patient as a unique human being’. He also emphasized the importance of examining the whole patient in order to make a diagnose (33). In 1984, Lipkin and colleagues expanded on this when defining the patient centered interview and included trust, confidence, and both biological and psychosocial dimensions of illness (34). Several definitions of the construct patient centered communication exist. One example from Langewitz and colleagues (35) is ‘communication that invites and encourages the patient to participate and negotiate in decision-making regarding own care’. Another example from Clayton and colleagues (2008) is ‘the degree to which providers respond to patient comments and concerns’ (36). For this thesis, the definition of patient centered communication was a communication style in which the patient’s perspective is the foundation for the dialogue, and social, psychological, and emotional aspects are acknowledged as equally important as somatic aspects. This definition was drawn from the definitions presented by Graugard and Finset (37) and Zachariae (38).

Literature is inconclusive in regards to patient centered communication’s impact on patient outcomes and patients’ preference for clinicians’ communication style. Some studies have suggested that a patient centered communication style has a positive impact on patient
satisfaction (39) and that patients preferred a patient-centered approach (9;38;40). However, a Cochrane review by Lewin and colleagues concluded that interventions to improve patient centered communication had mixed results. Out of 13 studies, less than half of the studies reported improved satisfaction and one study reported decrease in satisfaction (41). Also, only two studies found positive results on patients’ health care behavior, indicating that patient centered communication does not necessarily improve the effectiveness of treatment. Although commonly accepted as the definition of best care practices, studies have also indicated that patients do not always prefer a patient centered communication style. This has been eloquently discussed in a recent paper by De Haes (42). Swenson and colleagues conducted a study where they had patients watch videotaped consultations in which a patient centered approach and a doctor centered approach were used. When patients were asked which one they preferred, 69% preferred the patient centered version (43). Dowsett (40) found that patients preferred a physician centered approach in the part of the consultation where information about treatment was given. They preferred the information about disease and treatment to be given thoroughly and without any self involvement. This indicated that patients have a preference for knowledgeable clinicians and that they require thorough information about their disease. This is consistent with another study that found that patients were less satisfied with consultations where they had to ask medical questions (44;45). It is also consistent with Peplau’s theory that frames this study, in that patients need to have all their needs met for a successful establishment of interpersonal relations. One study by Graugaard and Finset tested standardized patients’ reaction to a patient centered versus a physician centered communication style. They found no difference between the two groups on emotional responses and satisfaction, but patients with high levels of state anxiety preferred a physician centered approach (37). Another study by McKingstry (46) that investigated patients’ preferences for a shared approach or a directed approach concluded that patients
vary in their desire for involvement. Eide and colleagues concur with this, concluding that cancer patients were less satisfied when physicians initiated socio emotional exchanges during physical examination (47). This means that clinicians may need to alternate between different communication styles during the consultation. Some parts of the consultation, such as the part where diagnosis and treatment possibilities are described, should be conducted by the clinician whereas other parts, such as taking the patient’s history and the part after diagnosis and treatment description, should attempt for a patient centered approach or patient activation. Different parts of the consultation call for different approaches, and the clinician needs to have the knowledge about this and tailor their consultation style to each patient’s individual preference.

1.5 Communication’s impact on patient outcomes

An increasing number of studies has attempted to describe the status of communication in health care, identified challenges and barriers of improved communication, and even suggested different methods of improvements. A common finding is that clinicians find communication with patients to be a challenging task, both when measured subjectively and objectively (12). The main challenges identified have been to elicit the patients’ perspective, to actively involve patients in the consultations, to provide patients with sufficient information, to deliver bad news, and to bring up sensitive topics such as psychosocial and lifestyle issues (17). Bringing patients perspective to the table can be challenging, but actively involving cancer patients in the consultation has repeatedly been documented to promote positive patient outcomes (48), such as reduced anxiety (49), increased satisfaction with care (41;44), increased adherence to treatment (50), information recall (51), and improved quality of life (44;52). Several reasons for clinicians’ insufficient communication have been elucidated. Examples given by Hack and colleagues (53) in a review of the literature were clinicians’ lack of time due to busy schedules and the clinicians’
impression that they know which information and to which extent their patients want to be informed. This resulted in clinicians underestimating the significance of patients’ communication needs and overestimating their own educated guesses for patients’ needs (53).

1.5.1 Communication about emotions

Previous literature has repeatedly demonstrated that clinicians struggle with the emotional parts of the consultations. One of the reasons is that patients mask their emotional worries as clues that are often difficult for the clinician to detect and respond to (54). Another reason is that clinicians often have limited time and are under the impression that discussing sensitive topics and giving emotional support are time consuming tasks (55). However, several studies have reported that discussing emotional issues does not increase consultation time notably (56-58). It is also a common misunderstanding among clinicians that discussing sensitive topics increase patients’ anxiety (59) or that patients are unwilling to address emotional issues (60), but in a study by Detmar and colleagues, almost all patients were willing to discuss emotions, and some patients even preferred to be asked if they needed emotional support (60). Clinicians have also reported lack of confidence in their own communication skills as a reason for struggling with emotional communication, resulting in a passive behavior when cancer patients expressed worries. The reason for this insecurity was described as a lack of proper training in how to communicate properly (16). A recent review of patient-physician communication also concluded that physicians lack communication skills (53). This review concluded that cancer patients continue to have unmet communication needs, and that communication outcomes were enhanced when physicians attended to patients’ the emotional needs. This is consistent with other studies that reported that physicians and nurses avoided asking their patients about emotional worries and also provided little emotional support. Clinicians used blocking behaviors such as ignoring patient statements and switching the subject back to biomedical aspects (17;57). In one study,
physicians have been reported to only respond to 10% of the empathic opportunities presented by patients (57) and another study revealed that nurses documented emotional issues as discussed in their charts without actually addressing them during consultations (17). A study by McCabe (2) concluded that even if nurses communicate well when using a patient centered approach, they often choose not to in order to protect themselves from difficult emotional situations, which emphasizes their insecurity.

Communication about emotions is particularly important in consultations with cancer patients, as they have been reported to have higher levels of psychosocial distress than the general population (49). Still, clinicians rarely initiate such discussions with cancer patients (61). Detmar and colleagues found that physicians only devoted 24% of the conversation time with palliative patients to issues regarding quality of life, and that emotional functioning was addressed in less than half of the consultations (62). Hargie and colleagues conducted interviews of cancer patients, and found that discussing existential matters was an important aspect of the consultation with nurses (63). Taken together, these findings demonstrate a mismatch of what patients need and what clinicians attend to that potentially may affect patients’ functioning, both emotionally and physically (55). Peplau also explained that patients lack the skills to express their feelings (25). Altogether, this suggests that patients and clinicians could benefit from communication support that facilitates and enhances emotional communication.

1.5.2 Communication about symptoms

A symptom is defined as ‘a subjective indication of a disease or a change in condition as perceived by the patient’ (1). According to this definition, the patient is the best source of information regarding symptoms. It is therefore crucial that clinicians obtain patients’ symptoms in order to find the right diagnosis, and to plan as well as evaluate the outcome of treatment and care. As symptoms are subjective, symptom experiences vary individually,
even within patients with the same diagnosis. Patients are therefore the experts of their own symptoms, and an important task for clinicians is to gain sufficient knowledge about each and every patient’s symptoms in order for them to effectively help patients manage their illness and the illness experience (50). This has been highlighted both from patients and from clinicians (64). Cancer patients tend to worry about physical symptoms and cancer survivors commonly interpret physical symptoms to be signs of recurrence. Lack of communication about symptoms may result in anxiety, lower self-esteem, sleep-problems, negative feelings and frustration (65). Still, several studies have reported that clinicians are unaware of patients’ symptoms (66;67), and that symptoms are mostly discussed if they are acute or obvious (62). Clinicians have been reported to underestimate the severity of patients’ symptoms (68), which can be a barrier for symptom management (69). Other studies have found that clinicians overestimate patients’ symptoms (70;71). One proposed explanation for this discrepancy in the literature was that patients’ worried that their symptom notification would be considered as complaining (72). Patients have explained that in order to be perceived as ‘good’ patients, they avoided asking questions or giving important symptom descriptions (73). Other studies have reported that patients described that it was difficult to ask questions (74).

Even if it is challenging to elicit patients’ symptoms, it is a necessity in cancer care (75). To demonstrate this; the two symptoms that are reported to be common amongst cancer patients, pain and fatigue, are also symptoms that are not being managed properly (53;62;76). Pain is reported to be a major concern for cancer patients, and if left untreated it will reduce both physical and psychological functioning (77;78). Guidelines have been developed by the World Health Organization (79), but failure to discuss cancer pain limits the possibility of pain management (48). Fatigue is a common side effect of cancer treatment, especially chemotherapy (80). Yet, a recent study by Clayton and colleagues found that only 58% of women with breast cancer mentioned fatigue to their clinician (36). These two symptoms are
both very subjective in nature; hence information about these symptoms must come from the patient. Cancer patients are exposed to poor continuity in care (22;81;82), and lack of time has also been described to hinder symptom assessment (53;75;82). A concern was expressed by the National Institutes of Health in 2002 about the lack of progress in symptom management in cancer care. As a consequence of symptoms frequently not being detected, they are not treated (22;83). Therefore, it is crucial that clinicians find effective methods to elicit patients’ symptoms.

1.5.3 Communication differences between physicians and nurses

Communication with patients is a frequently performed task by all clinicians (84). Within the health care team, nurses spend more time with the patients than any other health care professionals (85), a situation which provides an excellent opportunity for communication and establishing interpersonal relations. Although the interpersonal relationship with patients is central both for physicians and nurses, the focus of the two professions is different. Physicians’ main task regards diagnosis, treatment, and evaluating treatment, whereas nurses have a more holistic approach and focus on the consequences of disease and illness (86).

Previous studies have indicated that nurses’ communication skills are poor, especially regarding how to include their patients in the consultations (87). A previous review concluded that nurses’ communication skills deserve more attention, as nurses were reported to be instrumental and superficial (26). Another study went as far as describing nurses’ communication skills as ‘a source of concern’ (88). One explanation for this is the fact that nurses historically were encouraged to distance themselves from interpersonal relations with patients in order to protect them from emotional stress (89), and findings from studies as recent as 1991 still concluded that nurses used blocking behaviors for protection when
patients expressed emotions (17). More recent studies have described that even if patients reported lack of information and difficulties asking questions, they found that nurses were easier to talk to than physicians (20). In a study by Sørlie and colleagues, the satisfaction of patients in a surgical ward was mainly predicted by contact with nurses (85).

The purpose of physician-patient communication has been summarized by Ong and colleagues into three goals: creating a good interpersonal relationship, exchanging information, and making decisions regarding treatment (50). Yet, studies have found that patients, who were asked about satisfaction with care, were least satisfied with physicians’ interpersonal skills (11), and that physicians failed to identify patients’ desire for information (90). In a recent review, Hack and colleagues described a wide variety regarding patients’ preferences of participating in decision making, and concluded that physicians struggled in identifying individual patient preferences (53). Another study found that physicians were reluctant to give precise answers when cancer patients asked about prognosis (82).

In summary, communication between patient and clinician has been studied a great deal and still gain researchers’ attention. However, studies tend to investigate one profession at the time. For this reason, few studies have been able to compare differences or similarities in communication patterns between physicians and nurses.

1.6 Interventions to improve communication

A number of different interventions with the aim of improving communication has been tested. Some aim at the provider, such as communication training courses (56;91;92), and the development of guidelines and educational schemes (93), and some aim at the patient, such as prompt sheet (94;95), pre consultation prompting (96), written (97;98) or audio taped (99-101) information, and more recently computerized supports or assessments (102). One intervention that has proven to be successful is the interactive tailored patient assessments
Communication training courses have been developed as a result of poor communication skills amongst clinicians. Historically, communication training has not been given much attention during the education of physicians and nurses. Even if communication training is an integral part of the education of clinicians today, there is evidence that these skills are still insufficient. One explanation is that there are many practicing clinicians that were educated before communication skills training was part of the curricula, and as these clinicians have practiced for many years, they serve as a measuring point for younger clinicians. Another reason is that communication skills training during education is not transferred to the clinicians’ daily work. Communication skills training for practicing clinicians has therefore been developed and tested. Alexander and colleagues found that residents improved their communication skills regarding end of life-issues after attending a relatively short, intensive training course. Haskard and colleagues found that communication training of physicians resulted in patients being more satisfied with physicians’ information giving and with overall care. Boscart tested communication skills training on nurses, and found that a brief training changed nurses’ communication practice to be less authoritative and more solution focused. However, studies have also demonstrated that even if clinicians improve communications skills after training, the effects are not sustained.

Several studies have described that those patients who ask more questions also receive more information. Based on this scientific fact, interventions have been developed to make patients ask more questions. Studies have tested out the effect of a question prompt sheet given to patients prior to the consultation. A prompt sheet is a list of suggested questions that patients can ask their clinician in the encounter. The idea is that it will encourage patients to ask more questions and consequently receive more information. Although some studies found an increase in questions asked by patients during consultations
most of the studies conducted have concluded that the prompt sheet has limited value. In the study described above by Haskard and colleagues, patients were also trained in how to plan and organize questions for the physician in the waiting room just before the encounter. As a result, physicians were more satisfied with the data collection.

Lobb and colleagues found reduced anxiety when patients were provided with a written summary letter after the consultation, and Rawl and colleagues reported reduced anxiety in cancer patients that took part in a follow-up intervention that included visits either at the clinic or by phone. Although these two interventions appeared to be different, the active ingredient that eventually reduced anxiety was the same; it enabled patients to repeat important information again and again, leaving them with fewer unanswered questions and an increased feeling of control.

In summary, numerous interventions have been tested in order to improve patient-clinician communication. Although some have reported successful results, previous interventions have been time consuming either for clinicians or for patients. Also, the interventions have mostly been standardized. This calls for an intervention that can be integrated into the daily routine of a busy clinical environment and can also be tailored to each individual patient.

1.7 Interactive tailored patient assessments (ITPA)

Recently, interactive tailored patient assessment (ITPA) instruments have increasingly emerged in different health care settings. There are several reasons for the increasing popularity of ITPAs’ usability. Firstly, there is an increasing recognition that patients are the experts of their own experiences of symptoms, and that patient perspective is a valuable contribution to provide the best care possible. As mentioned above, clinicians have reported that it is a challenge to bring sensitive topics up in the consultation. However, ITPAs have been reported to be specifically useful to obtain data about sensitive topics.
Secondly, ITPAs are tailored to each individual patient’s needs. Standard methods, such as paper and pencil tests or the clinical interview, require that patients respond to all items included, which can be time consuming and stressful for patients. Because ITPAs allow branching into sections, patients are asked to respond only to the issues relevant to them. Consequently, superfluous questions can be eliminated and the follow-up questions from the clinician are relevant to the patient (113). It might be less of a barrier for the patient to use an assessment in which the response burden is decreased. In fact, in previous studies where patients have experienced both paper and pencil assessments and electronic assessments, patients reported a preference for electronic assessments (103).

Thirdly, ITPAs can easily be integrated into patients’ electronic health record and therefore be available to clinicians in real time (52;114). This enhances screening efficiency because data may be entered directly into the existing clinical databases and immediately be analyzed, summarized, and printed (112;115;116). This is an important argument for clinicians that are constantly under pressure regarding time, thus it is less of a barrier for clinicians to use it. Also, patients can complete ITPAs prior to the consultation in their own pace, avoiding taking time away from the clinicians. In fact, consultation time is likely to decrease as a result of patients’ indications of their perceived problems, because the clinicians no longer need to spend time investigating. Previous studies have demonstrated an association between the time of consultations and physicians’ responses to patients’ expressions of cues or concerns in descriptive studies without the use of ITPAs. The results showed that adequate responses to expressed concerns reduced the length of the consultations in primary care and surgical interviews (58), and in an oncology setting consultations were 4 minutes shorter when physicians responded to more than 90% of cues (49). This indicates that it is time consuming to elicit patients’ needs. When patients report their symptoms on an ITPA and the clinician has the assessment summary available during the consultation, clinicians can address
the patient reported symptoms rather than look for the patient’s expressions of cues. Patients who participated in a recent study assessing the feasibility and acceptability of an electronic symptom assessment also suggested that it would save time, because the clinician usually has limited time to spend on the consultation (103).

In summary, we know from previous literature that the use of ITPAs has positive impact on several patient outcomes. A number of different studies have reported positive acceptability, usability, and ease of use of touch screen ITPAs (52;69;102;103;114;115). However, we do not know what effect ITPAs have on the actual communication between clinicians and patients. More specific, we lack knowledge about the potential effect of ITPAs on emotional parts of consultations, task-oriented parts of the communication, and differences and similarities in physicians and nurses’ utilization of ITPAs.

1.8 The Choice ITPA

One example of an ITPA is Choice (Creating better Health Outcomes by Improving Communication about patients’ Experiences) developed first by Cornelia Ruland and further by her team of researchers and developers at Center for Shared Decision Making and Nursing Research at Oslo University Hospital, Oslo, Norway. The Choice ITPA is administered to patients on a tablet computer with a touch sensitive screen. According to the literature, touch pad computers are suitable and easy to use for all users (103), regardless of previous experience with computers or Internet activity (115;117). Although some studies found that elderly patients reported lower ease of use (114), most studies have found that vulnerable groups of patients, such as elderly, have an even greater benefit from using electronic tools (102). Peplau emphasizes that clinicians can not solely rely on patients to express their problems directly, but also look for hidden meanings (25). The Choice ITPA is an intervention that would facilitate the orientation phase of Peplau’s theory of interpersonal relation, as patients can more easily identify their problems and present them to the clinician.
Clinicians need information about patients’ problems and needs in order to solve problems and fulfill needs. This information can be obtained from the patient, from the patient’s records, or from other sources (28), and the Choice ITPA is an example of another source. According to Peplau, the interaction of clinician and patient is successful when communicating common meanings and the aim of the Choice ITPA is to facilitate this.

Prior to the current study, the Choice ITPA had been tested in a randomized controlled trial measuring the effect on patient care, symptom distress, and patients’ need for symptom management support (118). In this repeated measures RCT with lymphoma and leukaemia patients, patients in an experimental group that had used the Choice ITPA prior to their in-and outpatient consultations and the clinicians had the resulting assessment summary available were compared to a usual care control group. In the experimental group, significantly more symptoms and problems were addressed in patients’ charts, indicating that clinicians used the information in their care. Patients had also significantly less symptom distress and need for symptom management support during treatment and rehabilitation. In addition to testing the effect on patient outcomes, focus groups with clinicians who used the Choice ITPA in this RCT were also conducted. One of the most valued issues raised was that it was easier and quicker to get to the core of the problem (unpublished material). Finally, in depth interviews with 16 randomly selected patients that used the Choice ITPA were performed. Some results from these interviews were that patients felt an increased sense of self-management and control over their situation. Patients also described that when they indicated their problems on the Choice ITPA, they experienced it as easier to bring these issues up in the subsequent consultation (119). This is an important contribution to the knowledge regarding how to facilitate clinicians in bringing up sensitive topics. However, the study did not investigate the mechanisms by which these outcomes were achieved.
So far, we know that Choice is a valid and reliable ITPA (113), which is regarded as an important and easy to use tool for cancer patients, and is efficient and valuable for clinicians as well. We also know that it has a positive effect on patient care and on patient outcomes over time. However, we do not know exactly what mechanisms cause these positive outcomes. One proposed hypothesis was that when clinicians become aware of patients’ symptoms and problems, they would incorporate it into the consultation. This hypothesis implied that more symptoms would be addressed and that clinicians would become more patient centered. Another hypothesis was that patients, as a result of completing a Choice assessment, became more aware of their symptoms and problems, and that they would bring it up in the consultations. This hypothesis suggested that patients became more active participators. The aim of this project was to test the potential effects of the Choice ITPA on the communication between cancer patients and their clinicians.
2 Aim of the study

The overall aim of this research project was to test the effect of the Choice ITPA on patient-clinician communication. More specifically, the study aimed to test the effects of the Choice ITPA on:

- Number and types of symptoms addressed during consultations (Paper I)
- The information given by clinicians during the consultations (Paper I & II)
- The content of the consultations (Paper I)
- Patients’ participation during consultations (Paper I)
- Clinicians’ communication styles in the consultations (Paper I, II & IV)
- The communication patterns in the consultations (Paper III & IV)
- The differences or similarities of the physicians’ and nurses’ communication in the consultations (Paper V)

Even if the primary aim of the study was to test the effects of the Choice ITPA, we have also investigated the following research question:

- Which other factors than the Choice ITPA might have influence on patients’ and clinicians’ communication?

Two perspectives were used in order to test the potential effects. The first perspective is a relatively newly developed method to analyze the emotional part of the consultations, the Verona Codes of Sequence Analysis (VR-CoDES) (5), which was used in paper II at consultation level and in paper III and IV at utterance level. The second perspective is derived from Roter Interaction Analysis System (RIAS) (120), which is one of the most commonly used methods of analysis in communication research. This approach was used in order to evaluate the potential effect of the Choice ITPA on the consultations and was used in paper I at consultation level and in paper V at utterance level.
3 Material and methods

3.1 Design

This study was a controlled two-group clinical trial with a quasi-experimental design. Randomization of patients was not possible as this could potentially have contaminated the data. When providers are introduced to the Choice ITPA, they are likely to alter their communication style. This would potentially make it harder to detect group differences. The Choice ITPA was introduced to the participating wards with a thorough introduction about the background and the purpose of the ITPA to all staff. A parallel control group was therefore not available. Alternatively, in order to randomize patients, we could have used patients in different sites. However, this would eliminate the possibility of controlling for person-specific communication approaches.

3.2 Sample

Patient sample: A sample of 100 patients per group was estimated based on an effect size of 0.4, which was chosen as a result of a pilot study prior to a recent RCT testing the effects of the Choice ITPA on changes in symptom distress (118). We derived this estimation from a two-tailed independent t-test with a power of 0.8 and an alpha of 0.05 (121). Patients were eligible for inclusion if they were

- 18 years or older
- Admitted for treatment for leukemia, lymphoma, multiple myeloma, sarcoma, or testicular cancer, or who had an outpatient follow up within a year of treatment.
- Patients were required to have Norwegian language and cognitive skills to be able to read and fully understand the purpose of participating in the study.

From 239 patients eligible for inclusion, a convenience sample of 196 patients from two hospital wards and two outpatient clinics constitutes the total study sample of the project.
The sample included 32% male and 68% female patients, ranging from 18 to 80 years of age with an average age of 48.9. The most frequent diagnosis was lymphoma (57%) and the least frequent diagnosis was multiple myeloma (1%). Paper II, III, and IV included 196 patients in the analyses, and paper I and V included 193 patients in the analysis. The reason for the different number of included patients in different paper was that 3 consultations were lost due to technical data management problems.

**Clinician sample:** Clinicians were selected based on the likelihood of being employed at the ward for the duration of the study. Five physicians and 16 nurses consented to participate. However, seven nurses left the ward between data collection in the two groups. We replaced three, giving a total number of 19 nurses and resulting in nine nurses participating in both groups, seven participating in the control group only, and three participating in the intervention group only.

### 3.3 Procedure for data collection

Data were collected from outpatient consultations with physicians or admission interviews with nurses for inpatients. The procedure differed slightly, but both were planned in partnership with the management of each clinical site. Since the data were collected from multiple sites, research assistants (RA) were trained in collecting data. In addition to the candidate, four RAs contributed to the data collection, two in the control group and two in the intervention group.

Inpatients were recruited as they arrived to the ward. The RA came to the ward every morning and was given a list of patients being admitted that day by the ward clerk. RAs discussed with the nurses who participated in the study whether the patient filled the inclusion criteria or not. The admitting nurse first asked the eligible patients if the RA could approach
them. When approval was given, the RA explained the purpose of the study and asked for participation.

Outpatients needed to be asked in advance of their appointment, because those who agreed to participate in the study needed to arrive 20 minutes before the original consultation time. The physician provided the RA with a list of patients one week in advance. The patient list included patient diagnosis and time since last treatment in order for the RA to identify patients who filled inclusion criteria. The RA then called all eligible patients to explain the purpose of the study and asked for participation.

When patients agreed to participate in the study, they signed a consent form and questionnaires (demographics and PANAS, see below). Patients in the intervention group completed the Choice ITPA prior to the consultation as well. In both groups, all consultations were audio taped. The researcher was not present during the consultations, and the tape recorder was placed out of sight for the patients in an attempt to avoid patients feeling stressed by its presence.

3.4 Measurements / Questionnaires

3.4.1 Positive and negative affect schedule (PANAS)

Patients completed the Positive And Negative Affect Schedule (PANAS) (122) before and after the consultation. PANAS contains 25 positive and negative emotions with a five-point likert scale, and patients were asked to scale the severity of each emotion from very slightly (1) to extreme (5). The resulting scores is an indicator of the patient’s current state of anxiety.

3.4.2 The Choice ITPA

The layout of the Choice ITPA was carefully selected to provide the best optical view for all patients. The chosen fonts vary from 18 to 24 and the chosen types are Tahoma and Arial. The colors are green on yellow background, which is documented to be the color
selection that gives patients the best possible optical sense (123). The Choice ITPA was in this study administered to patients on a Fujitsu Siemens tablet PC with 12.1-inch screen and 1024X768 pixels. The tablet PC weighs 1.6kg and has a computer pen with which to touch the screen. The application is self explanatory, in that each slide includes an explanatory text.
The Choice ITPA has been through extensive usability testing, in initial phase with test-persons with computer competencies, and finally with the patient group it is intended to reach. Comprehensive and systematic search through the literature was followed by focus groups with patients and with providers (physicians and nurses) working with the specific patient groups (leukemia and lymphoma), and resulted in the final symptom list in Choice (118). In this way, the symptoms are thoroughly tailored to patients with their specific cancer diagnosis. In a previous version of Choice, the symptoms were listed in 19 problem categories, each of which triggered a subset of related symptoms. In the recent version that was tested in this project, the symptoms were organized in four main categories: 1) “physical symptoms and discomfort”, 2) “pain”, 3) “thoughts, feelings, and social relations”, and 4) “things that are difficult to do”. Each of these main categories has several subcategories, and when clicking a subcategory, the specific symptoms that patients can select appear. To illustrate this, the main category “physical symptoms and discomfort” contains the subcategory “nutrition”, which includes the specific symptoms “lack of appetite”, “weight loss”, “unable to drink sufficiently”, etc. The main category “thoughts, feelings, and social relations” contains the subcategory “mood”, which further includes the symptoms “angry”, “sad”, “anxious”, etc. When patients have selected the symptoms that apply to them, the system creates a list of the chosen symptoms, in which patients are asked to scale the degree of bother on a scale from 0 (not bothersome) to 4 (extremely bothersome) and to scale the prioritized need for help from a health care provider on a scale from 0 to 10. Finally, an assessment summary (example given in Figure 2) is printed and used in the subsequent consultation. Therefore, the Choice ITPA is not a substitute, but merely a supplement to the standard clinical consultation.
Figure 2 Assessment summary

<table>
<thead>
<tr>
<th>Priority for help</th>
<th>Symptoms</th>
<th>Otherness</th>
<th>Talked about</th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>Numbness or tingling in hands and feet</td>
<td>Extremely</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Anxious</td>
<td>Very</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Fear of dying</td>
<td>Very</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Worries for relapse or not getting well</td>
<td>Very</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Muscle or joint pain</td>
<td>Moderately</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Worries about side effects or complications</td>
<td>Very</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Difficult feeling inner peace</td>
<td>Very</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Feeling besides myself</td>
<td>Very</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lightheadedness</td>
<td>A little</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Unsure about possibilities for support and help</td>
<td>A little</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Uncertain about further treatment</td>
<td>Moderately</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Problems with bladder control</td>
<td>Moderately</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mood swings</td>
<td>Moderately</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Chills</td>
<td>A little</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Easily tired</td>
<td>Very</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Difficult concentrating</td>
<td>Very</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Tired from others' questions and concerns</td>
<td>Moderately</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hard to maintain normal roles with family or at work</td>
<td>Moderately</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Constipation</td>
<td>A little</td>
<td></td>
</tr>
</tbody>
</table>
3.4.3 Symptoms addressed

Symptoms were recorded according to the list of all 119 symptoms within the Choice ITPA to test if more symptoms were addressed in the intervention group. Two separate coders recorded the symptoms, and Pearson’s r was calculated as a measurement of inter-rater reliability (r=0.52).

3.4.4 Communication

All consultations were audio taped and coded. Two different methods for coding of the consultations were applied due to the different foci of the papers.

3.4.4.1 Verona Codes of Sequence Analyses (VR-CoDES)

Paper II, III, and IV: In order to best evaluate the emotional parts of the communication, the VR-CoDES (5) was used. This coding system provides consensus-based definitions for when to code a concern (defined as a clear verbalization of an unpleasant emotional state) or a cue (defined as an expression in which the emotion is not clearly verbalized but might be present and needs further investigation from the clinician) (Table 1), and likewise has rigorous categories for how to categorize the subsequent response from the clinician (Table 2). Cues and concerns are seen as significant sources of information on a patient’s fears and worries, and it requires different skills from the clinician to respond to a cue as opposed to responding to a concern. Cues as verbal or nonverbal hints to concerns would need further clarification and, therefore information gathering and facilitating skills to help patients express their concerns. Concerns may or may not demand exploration. In situations in which a concern does not demand exploration, an emphatic response or acknowledgment would rather be required (5).
The point of departure for the coding in the VR-CoDES is the identification of a patient expression within a patient’s turn which qualifies as a cue or concern according to the coding criteria. The unit of analysis for this coding was a turn, defined as the period when one speaker holds the floor in interpersonal exchange (124). The coding was performed in two steps; the first was to identify patients’ expressions of a cue to negative emotions or emotional concerns, and secondly the response from the clinician in the subsequent clinician turn was coded. Moreover, an assessment was made by the coder as to whether the cue or concern was initiated by the clinician in the turn preceding the cue or concern, or the cue or concern was initiated by the patient, without any elicitation by the clinician.

**Cues and concerns:** The coding system originally includes a total of nine different types of patient cues (seven types) or concerns (two types). For the purpose of papers in this study, we further synthesized the nine categories of cues and concerns into two broader classes; descriptive expressions of emotions (DEE) and hints to hidden emotions (HHE) (Table 1). These two groups, although not defined in the original manual of the VR-CoDES, was considered meaningful for these papers. It was discussed with members of the Verona Network, who concurred with this reasoning. DEE included concerns and cues A, C, D, E, and G categories, considered to be the most unambiguous utterances from patients. Concerns are explicitly stated (‘I worry about the test results’), and even if the cues are not explicit, they are more evident than the rest of the cues (‘I feel mentally exhausted’). HHE included cue B and F, which are defined in the VR-CoDES as hints to hidden emotions in terms of verbal (B) and nonverbal (F) expressions. Examples of cue B are ‘I hope the test results are good’ (expression of hope) and ‘I am wondering about my future’ (expression of uncertainty). Expressions coded as cue F are nonverbal cues, which are more difficult to code in audio taped consultations. Crying is the only non verbal cue that was possible to code from audio taped consultations.
Responses: Responses may be immediate or delayed, and the system differentiates between 17 individual categories of responses. Firstly, the distinction is made regarding the degree of explicitness in the response, and further regarding the space that is given by the clinician to each cue or concern expressed by the patient. These categories represent the five main categories of the system: non-explicit reduce space, explicit reduce space, non-explicit provide space, explicit provide space (content), and explicit provide space (affect), and also the categories of responses used to code the communication in this project (Table 2). The system intends to be descriptive in the sense that it does not normatively distinguish between what responses are good and bad. A response is a verbal or nonverbal expression from the clinician, following a cue or concern expressed by a patient, and it is not a priori given that providing space responses are better than reducing space responses.

<table>
<thead>
<tr>
<th>Type (vague or unspecified words to describe an emotion)</th>
<th>Patient utterance</th>
</tr>
</thead>
<tbody>
<tr>
<td>It has been tougher than I had imagined in my wildest imagination. I feel mentally very far down right now.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Descriptive expressions of emotions (DEE)</th>
<th>Patient utterance</th>
</tr>
</thead>
<tbody>
<tr>
<td>C (physiological or cognitive correlation to an emotion)</td>
<td>I vomited last night, probably because I knew I had this appointment today. I didn’t sleep last night, thoughts were spinning around in my head.</td>
</tr>
<tr>
<td>D (neutral expression that stands out)</td>
<td>This examination is important to me, as I had relapse about this time after the first treatment.</td>
</tr>
<tr>
<td>E (repetition of a previous neutral expression)</td>
<td>I believe that if I quit (antibiotics). . . I believe I will be ill. . . I dare not quit.</td>
</tr>
<tr>
<td>G (clear expression of a concern in the past)</td>
<td>I was worried when my blood counts dropped.</td>
</tr>
<tr>
<td>B (verbal hint to hidden concern)</td>
<td>I hope it won’t be worse than last treatment. I am very excited now. . . do I have weeks left or months. . . or a year? Is this normal?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hints to hidden emotions (HHE)</th>
<th>Patient utterance</th>
</tr>
</thead>
<tbody>
<tr>
<td>F (non verbal cue)</td>
<td>Doctor: we need to do a biopsy. Patient: oh? (sigh) I was hoping to avoid coming back here. . . (cries) I didn’t think it was enough time.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Concern without topic</th>
<th>Patient utterance</th>
</tr>
</thead>
<tbody>
<tr>
<td>The anxiety is there. Last night I was anxious.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Concern with topic</th>
<th>Patient utterance</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am a bit scared, scared for relapse. I have headaches, which reminds me of this every day and makes me anxious about relapse.</td>
<td></td>
</tr>
</tbody>
</table>

Table 1 Examples of cues and concerns.
<table>
<thead>
<tr>
<th>Response type</th>
<th>Definition</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-explicit reduce space</td>
<td>A response that neither refers explicitly to the cue/concern, nor opens up for further expansion of the cue/concern (e.g. ignore)</td>
<td>Pt: I’m so tired that it scares me sometimes Clinician: Mmm, and how is you tummy?</td>
</tr>
<tr>
<td>Non-explicit provide space</td>
<td>A response that does not refer explicitly to the cue/concern, but opens up for further expansion of the cue/concern (e.g. facilitation)</td>
<td>Pt: This tiredness has contributed to my anxiety Clinician: Mmm, are you currently on sick leave? Pt: After the last chemo it was a nightmare. I had a lot of mental problems. Clinician: OK. You were confused and felt that it was too much?</td>
</tr>
<tr>
<td>Explicit reduce space</td>
<td>A response that clearly refers to the cue/concern, but does not allow the patient to further expansion of the cue/concern (e.g. information-advice)</td>
<td>Pt: How many get relapse after stem cell transplantation? Is it about half, or . . .? Clinician: We need to categorize patients; it’s an individual situation. In your case it looks good. Pt: For how long do I need to worry about relapse? Clinician: The strangest things can happen, but the risk of relapse decrease exponentially with time.</td>
</tr>
<tr>
<td>Explicit provide space content</td>
<td>A response that clearly refers to the cue/concern, and allows the patient to further expansion of the content in the cue/concern (e.g. acknowledgement)</td>
<td>Pt: I dread this (chemotherapy) Clinician: Did you dread it more the first time? Pt: My job situation is difficult Clinician: You said (last time) that you would try working 20%?</td>
</tr>
<tr>
<td>Explicit provide space affect</td>
<td>A response that clearly refers to the cue/concern, and allows the patient to further expansion of the actual emotion (affect) in the cue/concern (e.g. empathic response)</td>
<td>Pt: I can’t sleep; I just think and think . . . Clinician: What do you think about? Pt: I feel terrible! Clinician: I understand that you feel that way.</td>
</tr>
</tbody>
</table>

Table 2: Examples of clinicians’ responses.

Coding and reliability: The VR-CoDES has been reported to be as successful as any other coding system in identifying concerns and cues to concerns, has demonstrated satisfactory inter-rater reliability, both for patients cues and concerns (5) and for clinicians responses (125) and high validity (126). A training package for coders is available (http://www.each.eu). Examples of coded communication from this data set are found in Table 1 (patient expressions) and Table 2 (clinician responses).
Professor Arnstein Finset, who is one of the developers of the VR-CoDES, was in charge of training a group of coders in how to utilize the system. For this project, two coders were selected and trained in using the system on a cancer population. These coders were partially blinded, meaning that they were not informed about the purpose of the study, nor had they any knowledge about the Choice ITPA. Complete blinding of the coders was not possible, as both patients and clinicians sometimes refer to Choice or the assessment summary during the consultations. The coders further performed consensus coding with me until satisfactory reliability was achieved. Inter rater reliability was measured based on ten consultations that they coded separately. The consultations were coded in random order, with one coding even numbered consultations and the other coding odd numbered consultations. When they both finished, all consultations were reference coded by me with satisfactory inter rater reliability (Cohen’s kappa 0.7).

3.4.4.2 Roter Interaction Analyses System (RIAS)

Paper I and V: To best answer the research questions for these papers, we applied components from one of the most used systems in communication research, Roter Interaction Analysis System (RIAS) (120). In addition, we applied the initiation component from VR-CoDES as described above. RIAS is tailored to the medical encounter. Coding rules and operational definitions can be mastered by non-linguists in a relatively short period of extensive training. High levels of reliability and reasonable coding speed are usually achieved with 6-8 weeks of practice (127). RIAS has been extensively used in coding medical consultations, including oncology care (47). RIAS has been reported to be a highly reliable system when applied by trained coders (50;128).

The unit of analysis is the verbal utterance, defined as the smallest discernible segment of speech to which a coder can assign a classification (120). RIAS consists of a detailed
classification system where each communication unit from both clinician and patient is assigned to one of 39 categories. When applying RIAS, each utterance is coded into one of 24 different task-oriented categories or 15 socio-emotional categories. However, as the emotional parts of the consultations in this project were investigated in other papers; socio-emotional exchange from RIAS was not coded again here. We categorized the patient utterances into one of the five categories medical, therapeutic, lifestyle, psychosocial, or other, which mainly compose the task-oriented component of RIAS. Each patient utterance was also classified as provision of information, open ended question, or closed ended question according to RIAS. As an additional evaluation of patients’ active participation, patient utterances were coded as patient or provider initiated according to the VR-CoDES. Similarly, clinicians’ responses were first categorized into one of the five task-oriented categories described above, and then classified as provision of information, open ended question, or closed ended question. Table 3 summarizes the coding applied in paper I and V.
<table>
<thead>
<tr>
<th>Communication categories</th>
<th>Coding scheme</th>
<th>Function in the data analyses</th>
<th>Inter rater reliability (Pearson’s r, Cohen’s Kappa)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient communication:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptoms</td>
<td>Choice</td>
<td>A measure of symptoms from the list of symptoms in the Choice ITPA discussed in consultations</td>
<td>0.55 ●</td>
</tr>
<tr>
<td>Physical symptoms and discomfort</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Things that are difficult to do</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thoughts, feelings, and social relations</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Utterances:</td>
<td>RIAS</td>
<td>Describes the content of the patients’ communication</td>
<td>0.8*</td>
</tr>
<tr>
<td>Medical</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Therapeutic</td>
<td></td>
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<td></td>
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<tr>
<td>Lifestyle</td>
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<tr>
<td>Psychosocial</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Initiation:</td>
<td>VR-CoDES</td>
<td>A measure of patients’ active participation during consultations</td>
<td>0.6*</td>
</tr>
<tr>
<td>Who started the utterance?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type of utterance:</td>
<td>RIAS</td>
<td>A measure of patients’ active participation</td>
<td>0.7*</td>
</tr>
<tr>
<td>Information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Open ended question</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Closed ended question</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinician communication:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinicians’ responses, category:</td>
<td>RIAS</td>
<td>Describes the content of the clinicians’ communication, measure the congruence between patients’ utterances and clinicians’ responses</td>
<td>0.8*</td>
</tr>
<tr>
<td>Medical</td>
<td></td>
<td></td>
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<tr>
<td>Therapeutic</td>
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<td>Lifestyle</td>
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<tr>
<td>Psychosocial</td>
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</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinicians’ responses, type:</td>
<td>RIAS</td>
<td>A measure of clinicians’ communicative behavior</td>
<td>0.7*</td>
</tr>
<tr>
<td>Information</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Open ended question</td>
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<td></td>
</tr>
<tr>
<td>Closed ended question</td>
<td></td>
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</tbody>
</table>

Table 3 Coding of paper I and V
The same two coders that coded the consultations for papers II, III, and IV were trained in how to code the consultations for paper I and V. The coders now had some knowledge about the Choice ITPA as a result of their previous work. However, they were still not informed about which group the consultations they coded belonged to, and they again coded in random order. The coder that had coded odd numbered consultations with the VR-CoDES now coded even numbered consultations and vice versa. After intense training and consensus coding, they coded ten consultations separately with satisfactory inter rater reliability. All consultations were coded by using Observer software (129) and then imported to the SPSS software (Chicago, Illinois), where analyses were performed.

3.5 Analyses

3.5.1 Analysis of VR-CoDES data

In paper II the level of analysis was the consultation. The numbers of cues and concerns and responses in the respective categories were counted in each consultation.

In papers III and IV the level of analysis was on turn level. The units of analysis were each individual cues and concerns, the subsequent response to the cue or concern and an indication of whether the cue or concern was clinician initiated or patient initiated, referred to as the source of the cue or concern. The source – cue/concern – response sequence constituted the basic unit for the sequence analysis performed in papers III and IV, the so called target unit. In paper III we also studied what predicted whether a target unit was followed by a subsequent cue or concern. Moreover, in paper IV we studied the potential effect of the immediately preceding basic unit on the response of the target unit.

3.5.2 Analysis of RIAS data

In paper I the level of analysis was the consultation. However, in paper V RIAS data were analyzed on utterance level, making it possible to analyze the congruence in terms of RIAS categories between a patient utterance and the subsequent clinician utterance.
3.5.3 Multi level analysis

In paper I and II, data on consultation level were nested within clinician. In paper III, IV and V the data structure was even more complicated, in that data on turn or utterance level were nested within consultations, which again were nested within clinicians. We therefore applied mixed models in the analysis of data.

For paper I and V, we exported the data from Observer and did all analysis in SPSS version 16. In paper I, the two groups were compared in a multilevel model with mean value per consultation at level one and clinician at level 2 (random factor). First we applied group (control versus intervention) as the only fixed factor. Then we applied a multivariate model, controlling for age and gender of patient, gender and type of clinician (physician or nurse), length of consultation, and pre-consultation negative affect. In Paper V, a simplified sequence analysis was applied, and groups were compared using cross tabulations and Chi².

For paper II, all descriptive analyses were performed in SPSS version 16 (Chicago, Illinois) and Poisson regression analyses were performed using R (Vienna, Austria). Due to the skewed data, we were unable to perform linear regression analysis. Group (control versus intervention), type of clinician (physician or nurse), patient gender, and clinician gender was applied to the equation as fixed factors and clinician identification as random factor. As consultation time was significantly longer in the intervention group, the results were tested in a second model, which also included time in the equation.

For paper III, IV, and V, sequence analyses were performed using PASW/SPSS version 18. The subsequent coded cue was added to the previous response, creating a sequence.

The effects of independent variables on clinician responses were examined in all cue/concern sequences. Moreover, the potential predictive effects of features of the preceding cue/concern sequence (Source, Explicitness, and Response) were tested in those consultations that were preceded by a cue or concerns earlier in the consultation (N=420).
In papers III and IV associations between independent and dependent variables were examined in all 580 cue/concern sequences. These associations were tested in multi level logistic regression analyses applying a Generalized Estimated Equations model. However, the model permitted to control for one level at a time only. We therefore controlled for the identity of the patient (there were only one consultation per patient) and clinician separately. These computations were performed in Predictive Analytics SoftWare (SPSS/PASW), version.

See the respective papers for further details on statistical analyses.

3.6 Ethical considerations

All patients in this study volunteered to participate by giving informed consent. They were told that they could withdraw from the study at any given point and without giving a rationale. The study was approved by The National Committees for Research Ethics in Norway (REK) and approved by the ethical board of the hospital. Except from the possible discomfort it would be for patients to have their consultation audio taped, participating in this study is not likely to cause patients harm in any way. Patients were not asked to participate if the clinician knew that they would give bad news regarding outcome of treatment, such as relapse of the disease or lack of effect of treatment given. In these circumstances, the admitting nurse informed the researcher not to approach the patient. These patients were still given the opportunity of completing the Choice ITPA, but they were not included in the study. All the patients approached knew that they had cancer, so there were no ethical concerns in asking them to participate in a study for improving the communication with cancer patients at their first admission.
4 Summary of papers – main results

4.1 Paper I

Paper I investigated the effects of the Choice ITPA on the task-oriented part of the consultations, and what effects the use of the Choice ITPA had on the communicative behavior of the patients and the clinicians. The specific aim was to test the number and types of symptoms addressed during the consultations, the patients’ active participation during consultation with clinicians, and clinicians’ responses. A total of 193 consultations were audio taped and coded with the task-oriented part of Roter Interaction Assessment System (RIAS). In addition, we recorded the initiator of each coded utterance (clinician or patient) as defined by Verona Coding Definitions of Emotional Sequences (VR-CoDES) and indicated the symptoms addressed in a list of all symptoms within the Choice ITPA. Of the 193 consultations, 99 were standard consultations that served as a control group. In the 94 intervention group consultations, patients used the Choice ITPA prior to the consultation, and the assessment summary was available to both patients and clinicians. By comparing the two groups in both multilevel and multivariate analyses, we found that significantly more symptoms were addressed in the intervention group as compared to the control group. We also found that patients asked more questions in the intervention group, indicating that they were more active participators when using the Choice ITPA. Clinicians provided more information to patients in the intervention group consultations.
4.2 Paper II

In this paper, the effect of the Choice ITPA on the emotional parts of the consultations was tested. With a quasi-experimental design, 97 experimental group consultations where patients used the Choice ITPA to report their symptoms and problems in preparation to their consultation were compared to 99 standard care control group consultations. All consultations were audio taped and coded using the Verona Coding Definitions of Emotional Sequences (VR-CoDES). Number and types of cancer patients’ expressed cues to negative emotions and emotional concerns (C&Cs), and the subsequent responses from physicians and nurses to these C&Cs were compared using Poisson regression analysis. In total 473 cues and 109 concerns with a mean number of 3.0 (SD=3.2) were identified. The most frequent utterance was cue B (45.2%), indicating expression of uncertainty or hope. More C&Cs were expressed by patients in consultations with the Choice ITPA compared to in the control group (p<.01), and in consultations with nurses compared to physicians (p<.001). No differences in clinicians’ response types in the two groups were found. However, significant differences in response type between nurses and physicians were found. The majority of responses from physicians were in the category ‘explicit reduce space’, indicating that they gave medical information or advices. Nurses generally responded in the category ‘explicit provide space’, indicating either facilitating or empathic responses. The conclusion was that the Choice ITPA was an effective tool to disclose cancer patients’ cues and concerns, but should be accompanied with communication skills training to potentially produce more patient-centered responses from the clinicians.
4.3 Paper III

The aim of this paper was to examine the impact of the Choice ITPA on communication of emotional cues and concerns expressed by cancer patients during inpatient and outpatient consultations in terms of: source of initiation of cues and concerns (patient or clinician); their sequence, explicitness; timing during the consultation; consultation type (inpatient/outpatient); and clinicians’ responses to patients’ cues and concerns. As in paper II, 196 consultations between cancer patients and clinicians were audio taped and coded by utilizing the Verona Coding Definitions of Emotional Sequences (VR-CoDES). However, differing from paper II, this study investigated the sequences in the consultations, which made it possible to investigate the effects of features the preceding cue/concern, or the clinician response, had on the target cue/concern. Direct and interaction effects were tested using multi-level analyses. A total of 471 cues and 109 concerns were expressed (mean per consultation 3.0). In the Choice intervention group there were significantly more frequent and more explicit expressions of cues and concerns; more clinician-initiated concerns occurred during the first ten minutes; and it was more likely for any cue or concern to be succeeded by a subsequent one. In consultations with many cues and concerns, these were on average more emotionally descriptive or explicit and occurred somewhat earlier in the consultation in the Choice group compared to the control group. Furthermore, more cues and concerns were expressed in inpatient consultations with nurses than in outpatient consultations with physicians. We conclude that the Choice assessment may be a useful clinical tool contributing to the disclosure of worries, fears and other feelings with less ambiguity than in consultations without Choice and thus can be a helpful tool to provide more patient centred care. This paper demonstrated that cancer patients’ expressions of cues and concerns do not occur at random. More cues and concerns are expressed early in the consultation, in consultations with nurses, and in the Choice intervention group.
**4.4 Paper IV**

The objective of this paper was to investigate the impact of patient, clinician and communication characteristics on clinician responses to patients’ emotional cues and concerns expressed in consultations with cancer patients. This paper reported findings from the same dataset that were coded with the VR-CoDES for paper III, where sequence analyses were applied. However, for this paper, it was the responses from clinicians that were investigated. The 196 patients included were treated for leukemia, lymphoma, testicular cancer, or multiple myeloma, with a mean age: 48.9 (SD=15.5) and 32% female. The clinicians included were five physicians (one female) and 19 nurses (17 females). Associations between variables were tested in multi-level analyses. There were 471 cues and 109 concerns with a mean number of 3.0 (SD=3.2) per consultation in the data-set. Clinicians provided more often room for further disclosure in consultations with younger patients, if the cue or concern had also been initiated by the clinician, if it occurred early in the consultation, if it was characterized by higher explicitness, and if it followed a preceding cue or concern that had been responded to by providing space for further disclosure. This paper demonstrated that responses of clinicians that provide room for further disclosure do not occur at random and are systematically dependent on characteristics of the clinicians and the patients and on the source, explicitness and timing of the cue or concern.
4.5 Paper V

The aim of this paper was to explore the content of task oriented communication of physicians and nurses, and how this might be influenced by the Choice ITPA, and how nurses and physicians respond to patients’ communication. Physicians and nurses have different roles in the health care team, and interdisciplinary collaboration is important to provide patients with the best care possible. Still, we know little about the differences and similarities in the communication patterns of physicians and nurses. Moreover, we know that interactive tailored patient assessments (ITPA) have been successful in improving patient-provider communication, but we do not know if and how physicians and nurses are differently influenced by utilization of an ITPA. Using the same sample of 193 coded consultations as described in paper I, the data were arranged as a sequence as opposed to counts, such as in paper I. Both physicians and nurses spent most of the consultation time discussing issues in the therapeutic category of RIAS, followed by medical content for physicians and lifestyle content for nurses. Nurses spent 11.1% of the consultation time on issues in the psychosocial category, compared to 3% for physicians. In the intervention group, nurses initiated more medical and psychosocial issues, and patients initiated more lifestyle issues in consultations with nurses. No differences in initiation patterns were detected for physicians between control and intervention groups. We found that when patients expressed psychosocial issues, the congruence with provider responses was good for nurses (81%) but low for physicians (32%). For all other categories, the congruence was good for both provider groups. The paper concluded that nurses’ communication patterns were influenced more by the Choice ITPA than physicians’ communication patterns, both in regards to giving patients more information, and initiating more topics.
5 Discussion

The discussion part of this thesis will be organized according to two main issues: the methodological aspects of the study and the main results from the papers.

5.1 Methodology

5.1.1 Design

This study used a quasi-experimental design, where study groups were sequentially enrolled and not randomized. Randomized controlled trials are considered the golden standard of research due to the possibility of testing one variable and control for any external sources (130). In this study, the aim was to test the effect of the Choice ITPA on the patient-clinician communication, and randomization would appear to be the best suitable design. Choosing a RCT would justify the conclusion that the Choice ITPA was the reason for the differences found between the two groups, rather than an external and possibly unknown source. However, when clinicians are introduced to the Choice ITPA, they are likely to change their communication style as a result of the symptom list from the patients. If clinicians alter their communication style, they would also apply this communication style with patients in the control group, who did not use the Choice ITPA, making it more difficult to detect any differences between the two groups. The Choice ITPA was introduced to all clinicians at the participating wards, as a new practice standard. Given this, we did not have a control group available to be tested at the same time, making randomization impossible. For this reason, a quasi-experimental design was chosen, where all control group consultations were audio taped prior to the introduction of the Choice ITPA. Changes that occurred during data collection in the control and the intervention group that potentially could influence the results were closely monitored, but no such changes were found.
5.1.2 Study sample

Patients were recruited using a convenient sampling approach, meaning that all patients who were admitted for treatment or appointed to the outpatient clinics within the data collection period and who filled the inclusion criteria were approached and asked for participation. In addition to filling the inclusion criteria, patients also needed to have a consultation with one of the included physicians or nurses.

Patients ranged from first time admission to the hospital for treatment up to one-year outpatient follow-up consultation after completed treatment. Although the majority of the patients were somewhere in the middle, meaning that they still received treatment, there is a possibility that the different time since diagnosis may have influenced the results. Patients that are newly diagnosed are likely to be concerned with grasping the realities of diagnosis, treatment options, and prognosis (22). During this stage it is likely that they do not yet experience many physical symptoms and even if they have many questions and thoughts, the shock might induce a state of ‘numbness’. Although this study did not include any consultations in which the actual diagnose was presented, it did include patients being admitted for treatment, both first time treatment and repeated treatment. Therefore, there is a possibility that some patients are still in shock during the consultation we audio taped. The next stage is when patients go through the chosen treatment. As a result of coping with treatment and managing the numerous side effects that follow this treatment, it is possible that patients were more concerned with physical symptoms. This was also suggested in a study by Graugaard and colleagues (131). Patients in follow up care, which no longer experienced physical symptoms, were more prone to be concerned about the long term side effects of treatment and psychosocial symptoms related to regaining life as it was before the diagnosis (22). This could have influenced the results of this study, as it was not controlled for in the analyses. For example, in paper V we compared patterns of communication between physicians and nurses. However, the consultations also differed on time since diagnosis,
which could potentially be the reason for the different patterns of communication. All consultations with physicians were outpatient consultations, whereas all consultations with nurses were admission interviews when patients were admitted for treatment. This was discussed as a limitation in paper V and emphasized here.

The patient sample varied widely in age, and it is likely that the clinicians communicated differently with the youngest being 18 and the oldest at 81 years old. Previous studies have shown that older patients preferred a doctor centered communication style (36;132) and that they also needed less information than younger patients (65). However, the patients’ ages were not statistically different between the control and the intervention groups, and this factor was unlikely to bias the findings of this study. The patients’ ages were also controlled for in the analyses.

Another factor that could have possibly biased the results is the skewed distribution of the participants’ genders. The distribution of 32% male and 68% male was a result of the convenience sampling described above. As previous research has reported that there are differences in communication patterns between male and female, such as more emotional discussions with female patients (133), it could be argued that the data collection should have aimed for a more even balance between the genders. Also, the clinician sample was skewed, in that 80% of the included physicians were male and about 90% of the included nurses were female. Gender has been studied more among physicians than nurses, and some of the findings reported are that male physicians more often interrupt their patients than female physicians do (134). Also, female patients ask more questions than male patients (62), and patients give more information to female physicians as well (135). Even if gender could be argued to influence the results, it is important to emphasize that the skewed proportion of gender, both for the patient population and the clinician population, was similar both for the control group and for the intervention group. It is therefore more likely that any potential bias
would be seen in the comparison between physicians and nurses, rather than in the comparison between the control and the intervention group. Both patients’ and clinicians’ genders were also controlled for in the analyses.

Lastly, there is a potential bias in the selection of clinicians. Clinicians who were asked to participate were told that the main purpose of the study was to test the potential effects of the Choice ITPA on the patient-clinician communication. Although it was emphasized that it was not the clinicians’ communication skills that would be studied, clinicians knew that their consultations would be audio taped. So it is possible that those who agreed to participate were those who were confident in their own communication skills. However, this would not influence the results in this study, as the clinicians for the most part were the same in both groups. In addition, it raises the question if the clinicians that are confident in their own communication skills are actually good communicators. Although this was beyond the scope of this study to compare clinicians’ and patients’ opinion on how they perceived the communication skills of the clinicians, other studies have found discrepancies in this area (91).

5.1.3 Method of data collection

There are different methods of collecting data in communication research. One frequently used method is to use different forms of subjective measures, such as questionnaires or interviews. Audio taping consultations provide an objective measure of the communication. A previous study found that there was a discrepancy in what clinicians said and what patients received (136;137). When going through a crisis, patients have different coping styles and management techniques, and this will also differ due to other factors, such as the time since diagnosis was given, the effect of treatment, previous experiences with the disease, previous experiences of being ill, and co morbidities. Some patients cope by holding on to hope, and as a result they are in denial of the negative implications or possible outcomes
that clinicians explain about their disease and treatment. Other patients might still be in shock during the consultation, and fear might block their ability to grasp any hope that the clinician provides. As mentioned above, patients in this study varied in time since diagnosis, and it is likely that they also differ in coping styles. For this reason, an objective measure can be argued to be the method that obtains the most correct data. Roter and Hall have argued that an objective measurement, such as audio taping, is the most optimal way of evaluating communication between clinicians and patients (138).

However, when audio taping consultations, there is a possibility that patients as well as clinicians alter their behavior as a result of the presence of the recording device and the knowledge of being studied. The finding from paper IV that clinicians provided more space in their responses early in the consultations compared to later could imply that they were influenced by the presence of the tape recorder from the beginning, and became less aware of it as the consultation progressed. For intervention studies, such as the present study, this effect will apply to both the control group and the intervention group. However, it is more likely that the communication in general was modified from how it would have been had it not been studied. Cautions were taken in an attempt to prevent the awareness of the study, such as placing the recording device out of the patients’ sight, and talking to the patients about non-disease related topics prior to the consultation. It has also been documented that patients tend to forget about the tape recorder after a few minutes (139). Even with so, we can not rule out the possibility that patients and clinicians to either a smaller or larger extent were affected by being studied.
5.1.4 Outcome measures

The consultations were coded with two different coding systems due to the different aims of the papers. It is important to use sound methods that capture the outcome being investigated. In paper II, III, and IV, the emotional parts of the consultations were investigated, and the VR-CoDES (5) was chosen as the best suitable coding system. The coding system as well as the description of how the coding was performed was thoroughly described in the methods in this thesis. The validity and reliability will be elaborated here. Although the VR-CoDES is a relatively new coding system for analyzing patient-clinician communication, an increasing amount of literature has emerged using this system. Mjaaland et al (140) used the system to analyze consultations in a general hospital setting, and Kale et al (141) coded consultations between immigrants and their physicians with the VR-CoDES. Vatne et al applied the system on a pediatric data set (142), and Grimsbø and colleagues applied it on email communication between cancer patients and oncology nurses (143). All these studies were conducted in different Norwegian settings, which strengthen the validity of the system for the current study. Prior to the development of the VR-CoDES it was difficult to compare results from different studies investigating emotional communication between patients and clinicians. Eide and colleagues has recently conducted a validation of the VR-CoDES (ref). Eide coded 12 consultations with the VR-CoDES and then watch the video taped consultation together with the patient. They concluded that the VR-CoDES to a large degree captured patients’ concerns.

RIAS is one of the most widely used coding systems in communication research and was used in a simplified version for paper I and V. A manual was developed for how to apply the simplified version. The simplification was made first and foremost because we already had analyzed the emotional parts of the consultations in other papers, but also because it shortened the training time for the coders. Previous literature has suggested that six to eight weeks of intensive training are needed to perform coding of the full RIAS manual (120). For
this simplified system, two coders that were already experienced in coding consultations with other coding systems spent four weeks training intensively. One could argue that this was insufficient training time compared to the recommendations, even if the recommendations have been made for the full RIAS coding. The two coders had recent experience in coding the consultations with a different system, and reached acceptable inter rater reliability. The elements of the coding where inter rater reliability reached the lowest agreement was in the category ‘other’, and regarding if the utterance was initiated by the patient or by the clinician. The element of initiation is taken from the VR-CoDES, and is not a part of the original RIAS coding. A recent paper that described the development of the VR-CoDES reported low inter rater reliability in initial stages of the development (5). As a consequence of the low reliability in this study, initiating was not emphasized when comparing the control and the intervention group.

5.1.5 Data analyses

The analyses in this study were complicated due to the fact that patient utterances were nested within consultations, which were again nested within clinicians. It is possible that clinicians had communication qualities that could potentially influence the result, giving the false impression that the intervention was the reason for these findings. As an example, if one clinician that commonly gave empathic responses happened to have consultations in the intervention group only, the results could be that more empathic responses were seen in the intervention group. However, this could have been due to this one person and not by the Choice ITPA. To avoid this, each clinician was assigned an ID number that was entered in the multi level analyses. However, the consultation itself was not controlled for. Hypothetically, there is also a possibility that features of each consultation could bias the results.
5.2 Main results
The discussion about the main findings from this study will be organized according to the aims of the study.

5.2.1 Symptoms addressed
One of the main findings from this study was that more symptoms were addressed when patients had used the Choice ITPA prior to the consultation than in standard care control consultations. This finding has important clinical significance, as failure to elicit patients’ symptoms may result in symptoms being untreated. Previous literature has reported that it is problematic for clinicians to elicit patients’ concerns about illness and treatment (144). As an example, pain is one of the most common symptoms among cancer patients, yet 25% of patients experiencing severe pain are not relieved from this pain (145). Literature has suggested that a comprehensive symptom assessment is necessary to manage pain, and that the subjective nature of the pain implies that patients’ self-report is best way to assess this symptom (78). Among the four main categories of the Choice ITPA, pain was one of the categories that gave a significant increase in symptoms addressed between the control and the intervention group. This indicates that pain is a symptom that clinicians and patients discuss rarely in standard consultations even if patients experience pain. Given that pain is a common symptom for cancer patients, and that the Choice ITPA increased discussions about pain, the use of the Choice ITPA is an easy to use intervention that prove to have great clinical implications. The finding that more symptoms were addressed concurs with the results from the previous RCT testing the effects of the Choice ITPA on patient outcomes (118).

As a consequence of more symptoms from the Choice ITPA’s assessment summary being discussed during the consultations, a reasonable and important question that arises is if fundamental issues are lost from the consultations to be replaced with patients’ perspectives. As described above, the Choice ITPA has never aimed to be a substitute for face-to-face communication, but was developed to be a supplement to the standard consultations.
Nevertheless, it is reasonable to attend to the possible dilemma that when the consultations are filled with more of the patient’s list of symptoms and problems, the clinician’s agenda may be diminished. Clinicians have a clear agenda for their consultations with patients, and although this agenda is different for physicians and nurses, all clinicians have a time frame in which they need to achieve their goals of the consultation. Consultations in the intervention group were on average four minutes longer than those in the control group, which could indicate that clinicians in this study chose to extend the consultations rather than omitting their own agenda. Although this at first seems to be positive, it is a possibility that clinicians chose to do so because they knew they were being studied and did not wish to appear as poor communicators. Clinicians have a heavy workload and work under a constant time pressure. Therefore, it is questionable if they will embrace an intervention that forces them to spend longer time on each consultation. The increase in consultation time from the control group to the intervention group was about four minutes. It is fair to say that the extra few minutes was time well spent considering that more symptoms were addressed and that patients received more information. Patients have repeatedly described consultations to be rapid, and requested clinicians to spend more time communicating with them (20). However, the reality is that for a clinician that attends to ten patients, there is a total delay in time of 40 minutes with the Choice ITPA. This being said, previous studies have opposite findings from this study regarding time, concluding that consultation time decreased as a result of clinicians being more patient centered (49;58). Brown and colleagues found that consultation time was reduced when cancer patients were provided with a prompt sheet prior to the consultations (51). What distinguishes the Choice ITPA to other interventions is the presence of the assessment summary with patients’ rank-ordered symptoms during the consultations, both for clinicians and for patients. The present study did not enable to observe possible changes over time, as each patient was recorded only once. However, a recent RCT testing the effects of the
Choice ITPA found that patients that used the Choice ITPA repeatedly had decreased symptoms and need for symptom management over time (118). This indicates that the first consultation with the assessment summary takes longer due to clinicians attending to more of patients’ symptoms. If the clinicians attend to the patients’ symptoms, it is likely that patients have fewer symptoms and need for symptom support after this, which evidently will decrease consultation time.

5.2.2 Information given

One of the main aims of clinicians’ communication with patients is the exchange of information between the two parts (50). As described in the introduction, clinicians have an important role both in information-seeking and information-giving (4). One of the main results from this study was the increased information given by clinicians to patients in the intervention group as reported in paper I. Previous studies have repeatedly found that cancer patients have a strong desire for detailed information about their disease, treatment, side effects, and prognosis (22;146), but that clinicians underestimate patients’ desire for information (50). The finding in paper I that patients receive more information when they used the Choice ITPA prior to the consultation seems clinically important and deserves further attention.

There are two possible explanations for this finding; the most obvious is that the printed assessment summary that was available to the patient, as well as the clinician, during the consultation encouraged clinicians to give patients information about the listed symptoms. The assessment summary contains information about the patient’s current problems and concerns, quickly providing the clinicians with a summary of what bother their patients. When used properly, it serves as a supplement for the clinician in addition to the regular questions that they need to ask. The other possible explanation is that the task of doing a
Choice assessment served as a prompting for patients, making them more aware of what questions they actually had. Cancer patients tend to be concerned about their prognosis and the outcome of their treatment in the meeting with their clinician. When they focus entirely on this, they often forget to bring up other issues that concern them. Literature has confirmed that patients that use ITPAs remember symptoms better in medical consultations (83;119). This was what patients that used the Choice ITPA in a previous RCT described during in depth interviews (119). They explained that using the Choice ITPA prior to the consultation enabled them to ask their clinician about issues that they otherwise would have forgotten to bring up. This was confirmed by the results from this study, in that more information was given and that more symptoms were addressed. Based on findings from previous literature it seems that interventions that aim at the patients are more likely to succeed than interventions aiming at clinicians (7). Therefore, the rationale for why clinicians gave patients who had used the Choice ITPA prior to the consultation more information was probably a combination of the two explanations proposed above; patients were reminded of their symptoms and problems, and clinicians were made aware of these problems, which facilitated bringing them up in the consultations.

5.2.3 Content of consultations

Paper I reported that the amount of time that was spent discussing psychosocial issues in the consultations was rather limited, but one of the findings from this paper was also that the Choice ITPA contributed to more frequent psychosocial discussion. One explanation for this is that even if psychosocial discussions were initiated more frequently, either by clinicians or by patients, these discussions were still short in duration. One natural question is therefore whether or not these short discussions are sufficient for the individual patient in order to be clinically significant. According to Lobb et al (97), it is the quality of the information given rather than the amount that seems to be important for patients, thereby
discussing psychological issues would significantly reduce anxiety. When clinicians become aware of patients symptoms and problems, they have the opportunity to attend to them. Attending to symptoms and problems of a psychosocial character might in some cases indicate referral to other members of the health care team, which does not necessarily take up much time. This being said, paper V found that regardless of the Choice ITPA, physicians responded to patients’ psychosocial utterances with psychosocial content in only 32% of the cases. This indicated that physicians switched subjects back to medical or therapeutic content, and has been described in other previous studies to be a mechanism used by clinicians (17). Also, paper II found that even if the patients gave more cues and concerns during consultations when they had used the Choice ITPA, the responses from clinicians did not significantly change as assumed. This provides rationale for the conclusion that communication skills training, particularly about psychosocial issues, still is needed. However, the provision of more information to patients, even if it is of a medical nature, might be important in their coping.

5.2.4 Patient participation

The main finding reported in paper II was that patients gave more cues and concerns when they had used the Choice ITPA prior to the consultations. In addition, the cues were clearer when patients used the Choice ITPA. Although the paper discussed what implications this result has for clinical practice, due to the word limit it did not discuss possible mechanisms as to why the number of cues and concerns increased. Two explanations of conflicting nature emerge. One is that the symptom list of the Choice ITPA made the patients worried, because they might have been afraid that they would experience all the symptoms listed in the system. When clinicians were introduced to the Choice ITPA and trained in how to introduce it to their patients, it was emphasized that the Choice ITPA lists all the symptoms
that the patients may experience before, during, or after treatment. This is also clearly stated in the introductory text in the program. Previous studies have reported that cancer patients commonly worry about symptoms, as they fear they are signs of recurrent disease (65). This is consistent with what patients that used the Choice ITPA explained in in-depth interviews: they constantly thought that the symptoms they experienced, such as fatigue, were signs of relapse or deterioration of the disease until they found the given symptoms in the Choice ITPA. They described that when the symptom was found in the symptom list of Choice, they interpreted this to mean that it was a common symptom and felt reassured (119). Given this, the explanation that the symptom list of the Choice ITPA worried the patients seems unreasonable.

The other explanation is that when patients went through the symptom list of the Choice ITPA, they were reminded of things they had questions about. In support of this explanation is a previous study, in which patients reported that an electronic patient care monitor report helped them remember symptoms they had experienced, and encouraged them to discuss these symptoms with their physician (102). Also, the fact that patients asked more questions in the intervention group, found in paper I, supports this explanation. Peplau described that patients tend to lack the ability to express their emotions (25), which can be caused by lack of motivation, skills, or knowledge in how to express oneself (22). Becoming a patient is not something we learn, and Peplau raised the important question ‘do patients know how to use help?’ (25). It is my opinion that the Choice ITPA serves as an important support for patients as well as to clinicians.
5.2.5 Clinicians’ communication style

Several findings from this study indicated that the Choice ITPA had more impact on patients’ behavior than on clinician behavior. Paper II described the effects of the Choice ITPA on patients’ expression of cues to negative emotions, and the hypothesis that more cues and concerns would be expressed with the Choice ITPA was confirmed. The hypothesis that clinicians would provide more patient centered responses, in terms of providing more room for further disclosure, when they had the assessment summary from the patients available during the consultation was not confirmed. As discussed in the paper, this indicates that the Choice ITPA alone is not enough for clinicians to change their communication style, and a combination with communication training was suggested. However, in paper I we found that patients asked more questions, and that clinicians gave more information when patients had used the Choice ITPA and the assessment summary was available to both the clinician and the patient during the consultation. This indicates a change in clinician behavior after all. In paper IV we found that clinicians provided more room for further disclosure of patients’ cues or concerns when they were the initiators of the cue/concern. Taken together, these findings suggest that clinicians are less comfortable when discussing psychosocial issues, which concur with previous studies (2;16;17;57;62). The communication skills training should therefore focus on how to bring up and discuss emotional topics with patients. This being said, paper IV also found that the less explicit the patients’ cues were, the less clinicians provided room for further disclosure. Often these cues were expressions of uncertainty, and in many cases biomedical giving information may be an adequate response (145). The intention of the Choice ITPA was to help patients convey their perceived symptoms and problems so clinicians could address them, and the interventions was not particularly designed to change clinicians’ response style to emotional consultation content.
5.2.6 Patterns of communication

Three of the papers in this thesis applied sequence analyses. This provided more insight in the different patterns of communication, both between control and intervention group, and between physicians and nurses. As Peplau’s theory frames this thesis, elements from her theory was brought into the analyses. Peplau described different phases of the interpersonal relationship, which can be interpreted to apply either to a prolonged relationship or to each consultation point, such as in this study. In paper III and IV we found that the different phases of the consultations affected both clinicians and patients. First of all, patients gave more cues and concerns early in the consultations compared to later in the consultations, and the cues patients gave in the early phases of the consultation were more explicit than the cues towards the end. In addition, cues and concerns given in early stages of the consultation were more often initiated by the clinician than by the patient. This indicates that clinicians are more active in eliciting patients’ problems and worries in the beginning of the consultation. Also, clinicians provided more empathic responses to patients’ cues and concerns in an early phase of the consultations (paper IV). Taken together, this might be an indication that clinicians tried to end the consultation. Clinicians have busy schedules, and are often under pressure regarding time. Only 44% of cues and concerns that were met with responses that reduced space for further disclosure were followed by a second cue or concern, as compared to 79% of those that were met with ‘provide space’ responses (paper IV). Another explanation for the difference in space providing responses at different phases of the consultation is the fact that clinicians knew that they were being studied. The possibility that they kept that in mind from the beginning of the consultation is present, and as a result of not wanting to appear as poor communicators, they altered their communicative behaviour. Even if this was the reason, it would not influence the effect of the Choice ITPA, as conditions were similar in both groups.
5.2.7 Impact of the Choice ITPA on physicians versus nurses

Due to having included both physicians and nurses in the clinician sample, it was possible to compare the two. Differences between physicians and nurses was found, both in terms of communication patterns in general, and regarding results with and without the Choice ITPA. One of the conclusions from paper II was that nurses seem to benefit more than physicians from patients using the Choice ITPA prior to the consultation. This was also suggested in a study by Mullen and colleagues (115), where nurses gave more favourable reports of the usability of a computerized assessment tool.

Paper V analysed the congruence between the content in patients’ utterances and clinicians’ responses. The Choice ITPA did not appear to have any influence on concordance. However, nurses and physicians differed in the psychosocial content category defined by RIAS. This category includes statements relating to psychosocial issues, such as feelings, emotions, and general state of mind (120). The obvious difference between physicians’ and nurses’ roles in the health care team is that the physician are mainly concerned with finding and treating a disease, while nurses are concerned with the consequences of the disease and treatment. Therefore discussing psychosocial issues may be more natural for nurses. Even if physicians change content, they might provide patients with information that is important for relieving patients’ worries. Still, given the fact that only 3% of patients’ utterances to physicians are within the psychosocial category, physicians’ response rate of 32% within the same category seems poor.
6 Conclusion and implications

This study is one of the first studies to test the effects of an ITPA on communication between cancer patients and clinicians in an actual clinical setting.

The main findings from this study can be summarized as follows:

- More symptoms were addressed when patients had used the Choice ITPA prior to the consultation.
- Patients asked more questions and clinicians provided more information in the Choice intervention group.
- Patients gave more cues to negative emotions and emotional concerns when using the Choice ITPA, and in consultations with nurses.
- The cues and concerns in the Choice intervention group was less ambiguous, despite the finding that the most frequently uttered cue was cue B (defined as the most ambiguous cue).
- Proportionally no difference was found between the control and the intervention groups in regard to if responses from clinicians gave space or reduced space for further disclosure. However, nurses provided significantly more space in their responses than did physicians.
- Patients’ expressions of cues and concerns did not occur at random. More cues and concerns were expressed early in the consultation, in consultations with nurses, and in the Choice intervention group.
- Clinicians’ provision of space for further exploration did not occur at random. The nature of these responses was highly and systematically dependent on characteristics of the patients and clinicians and on the source, explicitness and timing of the cue or concern.
- Both in consultations with physicians and with nurses, therapeutic issues were most commonly discussed, followed by medical issues in consultations with physicians and lifestyle issues in consultations with nurses.

- When patients’ utterances had psychosocial content, physicians responded with psychosocial content 32% of the times. For all other contents, congruence between patients’ utterances and clinicians’ responses was good.

The findings from this study have important implications for clinical practice and the study is also an important contribution to the literature of communication research. First of all, the Choice ITPA appears to be a useful support both for assessing patients’ symptoms and for the disclosure of worries, fears, and other feelings with a higher degree of explicitness. Patients became more active participators, and clinicians provided more information. In addition, the study gave more insight in other characteristics of the consultation, and this knowledge is important for future research on patient-clinician communication.
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