Patient-Physician Communication in Oncology Care

The character of, barriers against, and ways to evaluate patient-physician communication, with focus on the psychosocial dimensions

HANNA FAGERLIND
The overall aim of this thesis was to characterize patient-physician communication in oncology care with focus on the content and quality of the consultations from the perspectives of patients, oncologists and observer. Further, the aim was to explore oncologists’ perceived barriers against psychosocial communication in out-patient consultations. Finally, the aim was to evaluate different methods for evaluating communication in this setting.

Routine oncology out-patient consultations from two different hospitals were audio-recorded. After the consultations, patients and oncologists perceptions of the content and quality of the communication were assessed using a self-report questionnaire. A nation-wide survey was performed to assess oncologists’ perceived barriers against psychosocial communication. Finally, the audio-recorded consultations were used for evaluating inter-rater reliability and feasibility of two different communication analysis instruments.

Patient-physician consultations in oncology care are focused on the physical aspects of disease and treatment, both in terms of how often these issues were discussed and in terms of the amount of time spent on discussing them. Psychosocial issues, such as the disease’s effects on patients’ emotional or social functioning, are not always discussed during consultations, and the time spent on such discussions is limited. When psychosocial issues are discussed during the medical consultations, they are most often patient-initiated. Reasons for why psychosocial aspects are seldom discussed during the medical consultations can be the barriers concerning this kind of communication perceived by a large majority (93%) of the oncologists. Barriers against psychosocial communication were identified at organizational levels (including guidelines, routines, and resources) and individual levels (including physicians’ knowledge and attitudes).

Furthermore, this thesis shows that there are methods with high feasibility and reliability for evaluating the content of patient-physician communication, in large study samples in oncology care. The method (observation/self-report) and perspective (patient, physician, and observer) used when evaluating communication affects the results. This needs to be considered when choosing evaluation methods in intervention studies.

There are reasons to continue to evaluate, promote and implement promising ways of achieving better communication in clinical practice. Research should focus on how to overcome barriers against psychosocial communication.

Keywords: patient-physician communication, barriers, psychosocial, content analysis systems, clinical practice, communication

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List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.


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## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Preamble</strong></td>
<td>11</td>
</tr>
<tr>
<td><strong>Background</strong></td>
<td>13</td>
</tr>
<tr>
<td>The character and treatment of cancer</td>
<td>14</td>
</tr>
<tr>
<td>Experience of cancer</td>
<td>14</td>
</tr>
<tr>
<td>Psychosocial problems related to cancer</td>
<td>15</td>
</tr>
<tr>
<td><strong>Patient-physician communication in oncology care</strong></td>
<td>16</td>
</tr>
<tr>
<td>A theoretical communication framework</td>
<td>17</td>
</tr>
<tr>
<td>Patient-centered communication</td>
<td>19</td>
</tr>
<tr>
<td>Patients’ perspectives on psychosocial communication</td>
<td>20</td>
</tr>
<tr>
<td>Oncologists’ perspectives on psychosocial communication</td>
<td>20</td>
</tr>
<tr>
<td>Shortcomings and barriers against psychosocial communication</td>
<td>21</td>
</tr>
<tr>
<td>Improving patient-physician communication in oncology care</td>
<td>22</td>
</tr>
<tr>
<td><strong>Need for further knowledge</strong></td>
<td>28</td>
</tr>
<tr>
<td><strong>Aims</strong></td>
<td>30</td>
</tr>
<tr>
<td><strong>Study setting</strong></td>
<td>31</td>
</tr>
<tr>
<td>The Swedish oncology setting</td>
<td>31</td>
</tr>
<tr>
<td>Consultations at the Swedish oncology department</td>
<td>32</td>
</tr>
<tr>
<td>Gastrointestinal cancer</td>
<td>33</td>
</tr>
<tr>
<td><strong>Methods</strong></td>
<td>35</td>
</tr>
<tr>
<td><strong>Data Collection</strong></td>
<td>36</td>
</tr>
<tr>
<td>Patient-oncologist consultations (Paper I-III)</td>
<td>36</td>
</tr>
<tr>
<td>Communication content and quality questionnaire (Paper III)</td>
<td>37</td>
</tr>
<tr>
<td>Medical records – Medical decision making (Paper II)</td>
<td>37</td>
</tr>
<tr>
<td>Oncologist Survey-Barrier Questionnaire (Paper IV)</td>
<td>37</td>
</tr>
<tr>
<td>Data preparation and analysis</td>
<td>38</td>
</tr>
<tr>
<td>Communication analysis (Papers I-III)</td>
<td>38</td>
</tr>
<tr>
<td>Time analysis of consultations (Paper I)</td>
<td>40</td>
</tr>
<tr>
<td>Nationwide survey - Physician questionnaire (Paper IV)</td>
<td>41</td>
</tr>
<tr>
<td>Statistical analyses</td>
<td>41</td>
</tr>
<tr>
<td>Ethical considerations</td>
<td>43</td>
</tr>
<tr>
<td><strong>Results</strong></td>
<td>44</td>
</tr>
</tbody>
</table>
The character of the oncology consultations ............................................ 44
Qualitative characterization .................................................................. 44
Quantitative characterization .................................................................. 46
Content of consultations- Patients’ and oncologists’ perceptions .......... 48
Quality of communication ..................................................................... 49
Oncologists’ psychosocial orientation and perceived barriers .......... 49
Methods for evaluation of patient-physician communication .......... 52
Reliability of VCAS and MIPS global scale ........................................ 52
Feasibility of VCAS and MIPS global scale ........................................ 53
Coding difficulties with VCAS and MIPS global scale ...................... 53
Outcomes depending on perspective .................................................... 53
Discussion .............................................................................................. 55
The character of patient-physician consultations ............................... 55
Discussions concerning psychosocial aspects ....................................... 55
Focus on medical and physical aspects ................................................ 57
Barriers against psychosocial communication ..................................... 58
Measurement and evaluation of communication ................................ 59
Qualitative analysis ............................................................................ 59
Observational coding of communication ............................................. 59
Different perspectives on communication .......................................... 60
Thesis results in a theoretical perspective ........................................... 61
Implications for clinical practice .......................................................... 62
Communication skills training ............................................................... 63
Guidelines and quality indicators ......................................................... 63
Systematic use of PROMs in clinical practice .................................... 64
Implications for future research .......................................................... 65
Methodological limitations ................................................................. 66
Conclusions .......................................................................................... 69
Specific conclusions ............................................................................ 69
Content and character of communication ........................................... 69
Barriers and psychosocial orientation ................................................ 70
Methods for evaluation of communication ......................................... 71
Key messages ....................................................................................... 72
Acknowledgements ............................................................................. 73
Summary in Swedish/ Sammanfattning på svenska ............................... 77
References ............................................................................................ 80
Abbreviations

In this thesis, the following abbreviations are used.

**ANOVA**  Analysis of Variance
**BSC**    Best Supportive Care
**EORTC QLQ-C30**  European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire: QLQ-C30
**ePRO**  Electronic Patient Reported Outcome
**IAS**    Interaction Analysis System
**GI cancer**  Gastrointestinal cancer
**HRQoL**  Health-Related Quality of Life
**MIPS**  Medical Interaction Process System
**PPBS**  Physicians Psychosocial Belief Scale
**PRO**    Patient Reported Outcome
**PROM**  Patient Reported Outcome Measure
**PQC-VAS**  Perceived Quality of Communication-Visual Analogue Scale
**QoL**    Quality of Life
**RIAS**  Roter Interaction Analysis System
**VCAS**  Velikova’s Content Analysis System
## Key concepts

In this thesis, the following key concepts are used. Some of these may be defined otherwise in other contexts and publications.

| **Communication** | In this thesis “communication” is used to refer to interpersonal communication, i.e. the direct transmission of signals from a person (sender) to another (receiver), who meet in real life. Communication is something that creates connections and links people together. When we communicate we convey our thoughts, feelings, and views to other people (1). Both verbal and nonverbal components are required to enable effective communication. In this thesis the “communication” concept is primarily used to describe verbal and spoken communication with focus on the content, i.e. topics discussed. |
| **Family** | Includes both biological family, significant other, and other close social relationships, such as close friends and partners. |
| **Health-Related Quality of Life** | The term for those aspects of Quality of Life (QoL) affected by the disease, its treatment and care (2), defined as: “The value assigned to the duration of life as modified by the impairments, functional states, perceptions and social opportunities that are influenced by disease, injury, treatment or policy” (3). |
| **Patient-centeredness** | A concept which encompasses multiple aspects of the character of the patient-physician relationship. The following five key dimensions are often included in descriptions of patient-centeredness; the practitioner adopts a perspective including both physical and psychosocial aspects related to the disease; considers the patient as a person; shares power and responsibility; values the therapeutic alliance, and considers the effects of the physician, as a person, on the consultation (4). Patient-centered care, con- |
subsequently, is care that incorporates and executes these aspects. Furthermore, patient-centered communication executes these aspects in the meeting with the patient.

Psychosocial care  
In this thesis the “psychosocial” concept is used for areas concerning the individual’s social, psychological/psychiatric, emotional, role, cognitive, financial, and sexual functioning. The psychosocial aspects have been regarded as key aspects of patient-centered care (5, 6). Psychosocial care has the aim of relieving emotional distress and promoting wellbeing.

Psychosocial orientation  
Physicians’ attitudes towards discussing psychosocial problems and their perception of burden associated with treating psychosocial problems. The term is used in association with the Physicians Psychosocial Belief Scale (PPBS) (7).

Quality of life  
According to the World Health Organization Quality of Life (WHOQOL) working group, Quality of Life (QoL) is a “person’s perception of their position in life in relation to their cultural context and the value systems of that context in relation to their own goals, standards, and expectations”(8). QoL is also described as “a broad concept affected by an individual’s physical and mental health, level of independence, quality of social relationships, social integration, and added subsequently their personal, religious, and spiritual beliefs”(9). According to Joyce, “Quality of life is what the individual says it is” (10).

Utterance  
A complete unit of verbal speech with a content of its own. It can range from a section of a sentence to a whole sentence. An utterance is here used interchangeably with meaning unit, which are also words, sentences or paragraphs containing aspects related to each other through their content and context (11).
Dear reader,

The value of including a brief biographical account illustrating the researcher’s pre-understanding seems important, especially in a thesis where the researcher is studying another profession. The personal perspective of the researcher undeniably affects the focus of interest, the choices made during the research process, and interpretations of the results.

The research presented in this thesis is part of a larger research project aiming to evaluate the efficacy of two different Health-Related Quality of Life/Quality of Life (HRQoL/QoL) instruments as a means of individualizing cancer care and treatment in the oncology setting. An important intermediate outcome is communication, as HRQoL/QoL-results can only be effectively acted upon if they are discussed between the physician and the patient. What started as a search for valid and reliable instruments to assess communication in the larger research project (Paper I and II) led to a shift in focus for my research, towards the character of patient-physician communication and means of evaluating and measuring communication in oncology care. The results from Papers I and III, together with other published research findings, led my focus to the psychosocial aspects of communication and why these issues were not discussed more often during the consultations. This led to the decision to explore the oncologists’ psychosocial orientation and their perception of barriers against this kind of communication (Paper IV).

I have been involved in the main research project with focus on HRQoL/QoL measures in clinical practice since 2005, first as a research assistant and later on as a PhD student. During this period I have had the privilege of working closely with oncologists and oncology nurses, and accompanying them on medical rounds and meetings. Being involved in this research project has also given me the opportunity to meet many patients and their family members in various situations. I have met some patients in connection with their involvement in the HRQoL/QoL study, as they were filling out HRQoL/QoL questionnaires at the clinic. I have also met some of the patients individually for interviews about their views of the care offered and how they perceived the implementation of the HRQoL/QoL instrument in
clinical practice (not included in this thesis). Although I am neither an oncologist/nurse nor a patient, this research project has given me some concrete insights into these parties’ perspectives. These insights have been valuable and probably have affected my research interest and the way I interpret and discuss the results. Yet, I cannot claim to have full insight into either perspective. However, being an outsider also can have advantages, especially when combined with some familiarization with the area under study. This is particularly true, as an outsider may observe details that are taken for granted by an insider and therefore might go unnoticed.

My own profession, that of pharmacist, has helped me in understanding the symptoms, treatments, and side effects affecting patients with cancer. It has also helped me understand the medical terminology used by oncologists. My experience of patient-provider communication in the pharmacy setting has made me aware of the importance of communication in healthcare, and also of the challenges involved.

Studying and evaluating communication is difficult. Methods vary widely, especially regarding the detail level of analysis, how time-consuming the analyses are, and how difficult they are to master. The starting point of this research project has been to find valid and reliable yet feasible means of measuring communication as an outcome in a large intervention study. Hence the communication assessment approaches used have been pragmatic, focusing mainly on content of communication, as the content is what HRQoL/QoL measurement in clinical practice can affect. The way in which one communicates is equally important, but has not been included in the scope of this thesis.

Working with individuals suffering from severe diseases such as cancer is difficult, and the oncologists’ skills have to include handling highly specialized treatments and simultaneously attending to other patient-centered aspects. This thesis does not aim to blame oncologists for any shortcomings, but to elucidate possible problems in today’s patient-physician communication and highlight promising ways to improve the communication, especially concerning the psychosocial aspects of the disease. It is my hope, and the aim of doing this research, that the findings can contribute to the further development of oncology care, resulting in even better care for patients with cancer.

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Hanna Fagerlind, Uppsala, 7th November 2012
Background

A journey of a thousand miles must begin with a single step
Lao-Tse

Communication between patients and healthcare staff is essential for achieving good care and treatment. Communication helps the physician to diagnose and to offer the best care and treatment for the individual patient. High-quality communication in medical consultations improves many relevant outcomes, including patients’ recall and understanding of information, adherence to treatment, and subsequent health outcomes (12-14). The communication can also affect patient satisfaction with care (13, 15, 16) and emotional wellbeing (13, 14, 17). However, the nature of the consultation is affected by the patient-physician relationship which is complex, uneven and may be emotionally laden (18, 19).

Due to the importance and the complexity of patient-physician communication the area has been in research focus for some decades now, resulting in a large scientific literature related to problems and possible ways to overcome these problems. Yet, some aspects in this field are still relatively unexplored. This thesis focuses on aspects concerning the character of communication during routine oncology consultations. Further, it also focuses on barriers against psychosocial communication and possible methods for evaluating communication in oncology care.

Although patient-physician communication in oncology shares many of the general features of most patient-physician interactions, communication in this setting is distinct due to the disease’s character, including the high mortality risk, complex treatments, and severe side effects in combination with the stigma associated with the disease (20-23). The contact with healthcare, and especially the physician, is therefore crucial to the patients’ ability to cope with the disease and its treatment. The aspects that differentiate patient-physician communication in oncology from other settings are further described below.
The character and treatment of cancer

Cancer is the general name for a group of diseases that includes approximately 200 different diagnoses, which in turn can be segmented into an array of sub-groups. Although there are many kinds of cancers, all cancers begin with DNA changes in cells that make them abnormal, ultimately growing out of control. Untreated cancer can cause serious illness and death. Today, tumors are the second largest cause of death in Sweden (24), and about 55,500 persons are diagnosed with the disease in Sweden every year. The annual increase in the number of cancer cases has been 2.0% for men and 1.4% for women. The increase is partly explained by the ageing population, but also by the introduction of screening activities and improvements in diagnostic practices. The risk of being diagnosed with cancer during a lifetime is approximately 30-40%. Of those being diagnosed, the majority (~60%) are over 65 years old. The most common cancer diseases vary between different countries and cultures, due to demographic differences in age structure, fertility and death patterns, prosperity levels, and lifestyle. In Sweden the most common cancer diagnoses are: prostate cancer, breast cancer, colon/rectum cancer, skin cancer, and lung cancer (25).

There are many different cancer treatments available; the most common are surgery, chemotherapy, radiation therapy, and immunotherapy. Treatment options are continuously evolving and improving, and today more patients with cancer can be cured or live longer with maintained HRQoL than ever before. However, many cancer treatments have severe side effects, including fatigue, nausea, or bowel symptoms, that can greatly affect patients’ HRQoL.

Experience of cancer

The diagnosis of a life-threatening disease like cancer challenges the individual patient and the surrounding family in many ways. Individual patients’ experiences of being ill can only be understood in the context of their life settings, including their families, colleagues, and social networks. It includes patients’ feelings, fears of being ill, of possibly dying, and the disease’s impact on various functions, of physical, social, and emotional character (26).

When diagnosed with cancer many patients go through different stages of adjustment and acceptance. The initial response can be disbelief, denial, or shock. Some patients try to protect themselves from the implications of the disease by challenging the diagnosis or the health professionals (26). During this phase many patients have difficulties remembering and processing information. After the initial shock phase patients generally come to terms
with the reality of the diagnosis but may simultaneously experience significant distress and related symptoms like insomnia, poor concentration ability, and depression (26). As information about treatment is gradually understood, hope and optimism may compete with more distressing thoughts. In the best case scenario the patient ends up adapting to the diagnosis and developing long-term coping strategies. Not all patients follow these stages, and some can be in different stages simultaneously. Furthermore, some move backwards and forwards between stages in the adaptation process (26).

The disease experience can generate high levels of stress for the patients and the patients’ family (27). Family members can be greatly affected as they have to handle their own feelings, fears and practical consequences of the disease at the same time as caring for the ill person (26, 28).

Cancer has a distinct position in society, as it often has an unknown cause and the outcome is uncertain with a high mortality risk (29, 30). Cancer is also associated with stigma (22, 23) that can affect how individuals with cancer are treated. Some patients feel victimized or classified as a “sick person”, by the society. Specific social expectations emerge on how the patient should behave or feel, according to the sociology theory of the sick role (31). Cancer diagnoses believed to be caused by one’s own actions, like lung cancer, can be further stigmatized by blame (23).

Psychosocial problems related to cancer
Cancer and its treatments often have significant impact on patients’ lives, causing not only serious symptoms (such as pain and fatigue), but also leading to emotional distress and limitations in role functioning and social activities (32), as well as problems of existential, sexual, cognitive and financial character (22, 26, 33, 34).

Being diagnosed with cancer can cause severe psychological and psychiatric problems like distress, anxiety, depression, or a combination of these. The initiation of these problems is highly individual and can start or change during any phase of the disease trajectory, often in relation to critical points or points of transition, such as at diagnosis, at start of treatment, or before or after receipt of test results (35-38).

Research suggests that 35-50% of cancer patients meet the criteria for a psychiatric diagnosis such as depression, anxiety or clinically significant emotional distress (39-42).

Depression is the most common psychological symptom in patients with cancer and occurs on a continuum of severity from non-pathological sadness
to clinical syndromes associated with clear distress and disability (43). Severe symptoms of depression can lead to decreased treatment compliance, lower HRQoL, and increased desire for a hastened death (44, 45). Prevalence of depressive symptoms varies with cancer type and stage (46). Higher rates have been seen for end of life (47), and in specific cancer diagnoses such as pancreatic, gastric, and lung cancer (46).

Anxiety is also relatively common in patients with cancer. For some patients, anxiety levels can impair the ability to accurately assess real versus imagined threats. Anxiety can lead to many clinical consequences including less effective medical decision making (48), exacerbation of medical symptoms (49), and disruptions of oncology care (50). It is also associated with decreased HRQoL (45).

As psychosocial problems are common and can influence care and treatment negatively and lead to reduced HRQoL, healthcare personnel need to recognize and discuss these problems with their patients. If psychosocial problems are discovered, treatment and care can be offered/adjusted accordingly, which in turn could lead to improved treatment and care outcomes.

Patient-physician communication in oncology care

Communication between the patient and the physician in the oncology setting has gained increased attention during past decades. Communication is the primary tool by which the patient’s symptoms and problems are elicited, treatment choices are discussed and decided, and information is conveyed.

Patient-physician communication is characterized by the complexity of an interpersonal relationship, involving interactions between individuals in unequal positions. The consultation often concern issues of life and death, which can be emotionally laden for both parties. Further, communication can affect recall and understanding of information, adherence to treatments, and thereby treatment/intervention outcomes (12, 13, 16, 19). Communication can also affect patients’ satisfaction with care (13, 15, 16, 19, 51).

Patients’ individual desire for information is highly variable, despite identifiable trends depending on cancer-specific, cultural, or demographic factors (52, 53). Research shows that most patients want as much information as possible, and that physicians often underestimate the amount of information patients seek. Over one-third of patients with advanced cancer have reported unmet needs with respect to medical information and communication (54). One study showed that 98% of patients with cancer wish to be informed of their diagnosis and 87% want to receive all possible information, both good
and bad (55). However, not all patients want to have all information. Patients’ coping style is one factor influencing the preference for amount of information, “blunters” (those with a tendency to avoid threat-relevant information) want less information, while “monitors” (those with a tendency to seek threat-relevant information) want more information (56, 57). As preferences are individual and at the same time can vary during the disease trajectory, it is important to routinely check patients’ needs and wishes for information (53).

Despite patients’ wishes to be informed, misunderstandings are common, often caused by patients’ and oncologists’ different perspectives. Medical terminology, or words that have another meaning in non-medical settings like “negative/positive test”, or “progress on”, might confuse patients and lead to misunderstandings (58, 59). Even when physicians report speaking everyday language with their patients, neither patients nor nurses always perceived this to be the case (60). Patients often underestimate the disease’s severity and overestimate the likelihood for cure (52, 61, 62) or prognosis/survival time (63). The percentage agreements between patients and physicians are 64% for seriousness of disease and only 36% for probability of cure (64). Furthermore, a majority of patients understand their disease type and treatment regimen while fewer understand the extent of their disease and the intent of their treatment (65).

A theoretical communication framework

A framework of patient-physician communication has been developed and applied to the oncology context (66). The Feldman-Stewart framework identifies components that underlie the communication process and specify the interrelationship among the components in the oncology setting (Figure 1). Below is a brief description; for further information refer to Feldman-Stewart et al., 2005.

The framework is based on other communication frameworks (5, 67-71), but adds the concept that communication is intended to address the goals of the participants, as well as recognizing that messages also can be conveyed by silence. The goal aspect has been included in communication theory before (72), however it has not previously been treated as a driving force underlying communication. In the Feldman-Stewart framework, communication goals are regarded as one of four key components. It is described that each participant has communication goals and objectives that affect the communication. Each goal is an expression of one or more of the participant’s needs. Patients’ goals may include being able to understand the situation or plan the future. It can also be to get information and support in order to be able to formulate future goals. The oncologists’ goals may be making treatment
decisions, evaluating the patients’ health status, or adequately informing of test results. In Figure 1, the communication goals of the provider and the patient are referred to as “patients’/providers’ primary goals”. The framework also identifies “enabling goals”, which are steps that facilitate the enabling of the primary communication goals.

The second key component is the participants’ attributes, including their needs, skills, values, beliefs, and emotions. Because the communication is a direct function of the attributes of each person involved, these attributes affect both how and what the participants communicate. These attributes might also affect the individuals’ expectations and understanding of messages received.

The third key component in the framework is the communication process i.e., the conveying and receiving of messages. In Figure 1 all these messages are referred to as just “messages”. They can, however, be either verbal, nonverbal or passive; lack of action or response can also be intended or interpreted as a message. Messages can be conveyed intentionally or unintentionally, and multiple messages can be conveyed and received at the same time. Verbal messages refer to messages that are expressed, either via talking or other modes of expression such as sign language. Nonverbal messages include tone of voice, facial expression, and body language.

Figure 1. Feldman-Stewart communication framework (66).
The final key component in the framework is the environment or setting in which the communication occurs. This includes social, cultural, legal, and physical aspects that influence the participants and the way in which they communicate. The environmental factors affect communication as it sets the limits and frames for what is perceived as acceptable to discuss in a specific setting.

The Feldman-Stewart communication framework can generate hypotheses about mechanisms that underlie research findings and suggest ways for further interventions and research (66, 73). The framework has been used in this thesis to interpret the results and to provide a basis for Paper IV in terms of what areas can affect perceptions of barriers against psychosocial communication.

**Patient-centered communication**

Patients do not only differ in the amount of information they want; they also differ in what kind of relationships (authoritarian/lenient) they want to have with their oncologists (19) and in their preferences concerning shared decision making (53). Although the majority of studies that have measured patient preferences for involvement in decision making, have found that a collaborative role or shared decision making (74-78) and a patient-centered physician communication style are preferred by most patients (79, 80). Patient-centeredness includes identifying and responding to patients’ ideas and emotions regarding their illness and reaching a common ground about the illness, and its treatments (21). Patient-centered care has been put forward as a gold standard of modern healthcare. One aspect of patient-centered care is communication. The psychosocial communication has been explicitly referred to as one essential component of patient-centered care due to the importance of understanding the patient within his/her unique psychosocial context (6). Patient-centered communication builds on patients’ needs being actively sought and on inviting the patients to participate in medical treatment discussions. However, it also includes respecting patients who want to have a passive role. Patient-centeredness cannot be explicitly explained by the Feldman-Stewart framework, however the framework can help explain why patient-centered communication sometimes succeeds or fails, due to the elements that interact in the communication process.

Increased involvement in decision making can increase satisfaction with the consultation (78, 81). It can also increase satisfaction with the amount of information received and the emotional support provided by the physician (78). In addition, it can lead to better HRQoL in terms of physical and social functioning and less fatigue (82). However, some patients still prefer a physician-centered style (80) and want the physician to take full control over the
treatment decisions. Not being responsible for the treatment choices can be helpful if the treatment fails, which otherwise can be an extra burden for the patients, who blame themselves and might experience feelings of guilt (26).

Research shows that the most effective physicians who use a patient-centered communication style incorporate nonverbal behaviors like maintaining eye contact, nodding to indicate understanding, and avoiding distracting movements (21). These physicians also use verbal behaviors like avoiding interruptions, encouraging patient participation, seeking patients’ beliefs, needs, values and preferences, and discussing patients’ emotions as well as the patients’ social contexts and relations (21).

Patients’ perspectives on psychosocial communication

There is a growing body of evidence showing that communication needs of cancer patients encompass disease and treatment concerns as well as psychosocial issues (52). Multiple studies have shown that most patients want to discuss psychosocial issues with their attending physician (83-87), and that most patients prefer to discuss psychosocial issues with their physician instead of with other professionals, such as psychotherapists (86, 87). However, patients differ in how much they want to discuss psychosocial issues and can also change preferences during the disease trajectory (35-38).

Studies have found that both patients and oncologists hesitate to bring psychosocial issues up for discussion, possibly leading to these issues not being sufficiently evaluated and treated (84). One study found that only 50% of the patients who before the consultation said that they would initiate discussions of social activities during the consultation actually did (85).

Oncologists’ perspectives on psychosocial communication

Physicians caring for patients with cancer are increasingly expected to remain up-to-date on the latest diagnostic and staging modalities, treatment regimens, and clinical trials. In addition, oncologists are expected to communicate effectively with patients and families regarding psychosocial matters and to seek patient participation in medical decisions. The specific skill of providing patient-centered communication varies between individual physicians, and does not automatically develop with experience. The skill can, however, be improved and learnt (88, 89). Physicians often find it difficult to address, and talk about psychosocial issues with patients (90-92). Studies show that oncologists often experience emotional strain from working with patients with cancer, and many develop strategies to protect themselves from emotionally distressing situations (92). One way some oncologists handle this during consultations is by being positive, and avoiding asking questions
which might elicit patient distress. Another strategy is blocking patients from expressing distress (92).

**Shortcomings and barriers against psychosocial communication**

Communication is difficult and the scientific literature shows problems in patient-physician communication in oncology care, such as symptoms not being elicited or addressed (93), poor ability to correctly detect clinical levels of distress (94), and inappropriately low referral rates to support services (95). Furthermore, many patients experience unmet needs during consultations (52, 96-101).

Physicians have been found to pay little attention to patients’ psychosocial concerns (102-104), and psychosocial issues are infrequently discussed with patients with cancer (85, 87, 105-108). These issues can, at least partially, be explained by oncologists finding it difficult to address, and talk about, psychosocial issues with patients (90-92). The reason for this could be due to barriers at both organizational and individual levels (109, 110). Potential barriers to implementing evidence-based psychosocial care has been suggested to include **predisposing factors** (e.g. oncologists’ values), **enabling factors** (e.g. time and resources), and **reinforcing factors** (e.g. feedback) (110).

**Predisposing factors** influence motivation to behave in a specific way. Many oncologists find it difficult to assess and address psychosocial issues with their patients (90-92), due to ambiguity in evaluating depression and anxiety, and/or dealing with uncertainties and denial (111). Furthermore, some worry that such discussions can upset or hurt the patient (112), or force an emotional bond between doctor and patient (113). Some oncologists protect themselves from emotional distress by limiting close contact with patients (92).

**Enabling factors** facilitate a behavior. Having enough time for the medical visit is one enabling factor. Limited consultation time may work in the opposite direction, preventing discussions of psychosocial issues (110) and resulting in misclassification of patients’ psychopathological symptoms and inadequate referrals to psycho-oncology services (90, 91). Knowledge about oncologists’ views on barriers against psychosocial communication is limited and studies suggest a need to further explore these in the oncology setting (110).
Improving patient-physician communication in oncology care

Due to the acknowledgement of the problems in patient-physician communication in oncology care, several interventions have been developed and evaluated. Interventions have aimed at affecting the behavior of the physicians, the patients, or both. Traditional interventions aiming at affecting physician behavior are communication skills training or the implementation of new guidelines. Interventions aiming at affecting and empowering patients include introduction of prompt sheets or providing patients with audio recordings of the consultation. An intervention aimed at affecting both the patient and the physician is the introduction of Patient-Reported Outcomes Measures (PROMs) in clinical practice. Some of the most common interventions approaches are presented further below.

Communication skills are not just inborn qualities or byproducts of professional experiences, but require specific proficiencies which can be improved by training (88, 89, 114). Interventions focused on affecting healthcare providers’ behavior have frequently included some kind of communication training program (115-119), often including theoretical information, role play, feedback, and discussions (116). Communication skills training can improve healthcare providers knowledge, confidence, and psychosocial orientation (116, 118).

Guidelines have been introduced to standardize management of patients’ emotional and social problems. The National Institute for Clinical Excellence (NICE) guidelines in the UK recommend psychosocial issues to be routinely assessed and discussed during oncology consultations (120). Guidelines for patient distress management have been introduced by the National Comprehensive Cancer Network (NCCN) (121), which defines distress in psychological, social, and spiritual terms (121). In Sweden the National Board of Health and Welfare has introduced psychosocial aspects in the National Guidelines for breast, colon, and prostate cancer care (122), which highlights the importance of psychosocial care for this patient group.

Interventions aiming at empowering patients have also been developed, including prompt sheets (123-126), audiotapes (127, 128), and coaching sessions (117, 129). The literature suggests that some types of patient-based interventions may be beneficial in specific aspects, like an increase in the number of questions asked or improved patient satisfaction with communication (129). However, there are few consistent findings and the outcomes measures vary substantially across studies, making conclusions hard to draw (129).

Another approach is the introduction of PROMs such as HRQoL measures into clinical practice to enhance discussions regarding factors related to pa-
patient-centeredness (130), including both physical and psychosocial aspects important to patients (131-133). Introduction of PROMs in clinical practice could contribute to a more informed medical decision-making process and thus to better treatment outcomes. Previous studies show that the use of HRQoL assessments in routine oncology practice may have positive effects on patient-physician interaction, on detection of psychological morbidity, and on the emotional wellbeing of patients (132, 134). Based on the communication framework described earlier, PROMs can affect patients e.g., by improving their skills to report and describe symptoms assessed by the PROM (135). It could also make health care providers aware of possible discrepancies between patients’ actual problems and the issues that patients spontaneously initiate during the consultation (135).

Research methods for evaluating communication

Valid, feasible, and reliable methods for measuring and evaluating communication are needed for studying possible improvements due to interventions, and for studying the routine consultation for research purposes (13, 116, 123, 125, 129, 136). The methods most often used include medical records audits, patient/physician self-report questionnaires/interviews, and non-participant observations (137).

Medical record audits

Medical record audits may be useful in documenting observable actions linked to communication, such as medication prescriptions and referrals. They are, however, less helpful in evaluating more general communication behaviors, as these are not systematically noted in the medical records (138, 139).

Self-report questionnaires or interviews

Self-report questionnaires, especially for assessing the patients’ perspective, are a common method, primarily when audio- or videotaping is not feasible. Questionnaires are a non-intrusive and time-efficient way of obtaining information. Many self-report questionnaires are developed for specific research projects, although there are instruments like the EORTC-QLQ-INFO26 questionnaire developed for evaluating patients’ perspectives on information received in consultations (140, 141). There are also scales developed for patient satisfaction with communication (142, 143). However, self-reporting can be affected by recall bias (faulty recall of conversation from memory lapses and/or social desirability), and may be distorted when treating sensitive topics (21). The method also requires that respondents have sufficient writing and reading skills. Furthermore, self-report cannot provide information on detail level, such as number of open-ended questions, or amount of time spent on discussing various topics.
The consultations could also be assessed by interviewing the participants after the consultation. Interviews could generate similar information as a self-report questionnaire, but could also provide a deeper understanding and explanations to the participants’ experience of the consultation. However, interviewing is time-consuming, and hence often not feasible in a clinical setting.

**Non-participant observations**

The use of audio- or videotaping for assessing consultations allows the researcher to observe and analyze the consultation without being present. The advantage of observation methods is that they are analyses of the actual situation, and not participants’ perceptions of what happened. Therefore, observation could be regarded as a more objective method, and a method which can give more information in terms of details, i.e. number of questions asked, who initiated a topic, etc. Several systematic instruments have been developed for coding, quantifying, and scoring audio-recorded patient-physician dialogues (51, 106, 108, 144-147). Disadvantages with these methods for evaluation are missing information due to poor sound quality, missing information conveyed before and/or after recording, and consideration of social desirability affecting the consultation content by changing participants’ behavior.

**Communication analysis-observation**

The most commonly used instruments for assessing observations in oncology care are the Roter Interaction Analysis System (RIAS) (144), CNLOGIT/Cancode (108, 148) and the Medical Interaction Process System (MIPS) (145). These instruments are interaction analysis systems (IAS), and evaluate the communication in detail, coding each utterance both in terms of content and in terms of mood (e.g. emotional utterance, negative or positive tone of voice). IAS can for example give information on the number of open-ended questions asked or the amount of adequate responses to patients’ emotional cues. As IAS are complex they require specific training courses (144, 145). Furthermore, the coding time for IAS is 3.5-5 times the consultation length (145, 147). Due to the time it takes to do the analysis, IAS is sometimes difficult to use in larger studies. Another limitation is the analysis detail level, which leads to a loss of holistic perspective of the consultation. This limitation has been acknowledged by the IAS-developers, who have introduced global rating scales accompanying the IAS, e.g. the MIPS global scale (145, 147).

**MIPS Global Scale**

The global aspect, i.e. the culture of the consultation as a whole, is interesting in evaluation of the effects of interventions for improving the patient-physician communication. This is so because the overall aim of many inter-
ventions is to affect global issues like “patient centeredness” or the “psychosocial focus” of the consultations. These aspects cannot be measured with quantitative instruments like IAS. Therefore, a more holistic approach, emphasized by both developers of RIAS and MIPS, is to add an evaluation of the communication on a global level (145) (see Table 1). The MIPS global scale is a further development from the RIAS global scale. The global scale alone, however, gives no quantifiable information on specifics in the communication, nor on the what or how aspect.

Table 1. Areas assessed in MIPS global scale

<table>
<thead>
<tr>
<th>General Interview ratings</th>
<th></th>
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<tbody>
<tr>
<td>Patient-centeredness</td>
<td></td>
</tr>
<tr>
<td>Patient-directedness</td>
<td></td>
</tr>
<tr>
<td>Psychosocial focus</td>
<td></td>
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<tr>
<td>Satisfaction with comm</td>
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</table>

<table>
<thead>
<tr>
<th>Patient ratings</th>
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<tbody>
<tr>
<td>Anxiety</td>
<td></td>
</tr>
<tr>
<td>Assertiveness</td>
<td></td>
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<tr>
<td>Patients’ involve</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Significant other rating</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td></td>
</tr>
<tr>
<td>Assertiveness</td>
<td></td>
</tr>
<tr>
<td>Involvement in treatment decision making</td>
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</table>

<table>
<thead>
<tr>
<th>Clinician ratings</th>
<th></th>
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<tbody>
<tr>
<td>Friendliness</td>
<td></td>
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<tr>
<td>Sensitivity</td>
<td></td>
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<tr>
<td>Quality of comm</td>
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</table>

Velikova’s Content Analysis System (VCAS)

Due to the detailed information and the coding time associated with IAS, a choice sometimes has to made between comprehensive analyses of a selected smaller number of randomly or purposefully selected consultations, or analysis of all consultations using a simpler, briefer analytical method. Selection of a smaller number of consultations in a large study can negatively affect the statistical power of the study. The research question at hand must guide decisions of whether an in-depth analysis of the interaction of communication is needed, or if the mere content is sufficient. Owing to these issues, simplified content analysis systems of checklist character have been developed. One of them is Velikova’s Content Analysis System (VCAS).
VCAS is influenced by Bird and Cohen-Coles’s model of a medical interview (149). The model is useful for structuring the analysis of consultations and distinguishes between three interview functions. These include collecting information to determine the nature of patient problems, responding to patients’ needs, and educating patients about the illness and treatment (149). Originally, VCAS was developed for a study-specific purpose of measuring whether HRQoL aspects included in the European Organisation for Research and Treatment of Cancers (EORTC) HRQoL-instrument, EORTC-QLQ-C30 (150), were discussed during consultations in an intervention study (132). VCAS contains several content areas. Symptoms and functions in VCAS are derived from the EORTC-QLQ-C30 (150), including bowel, nausea, fatigue, emotional and social functioning. For a complete description of content captured by VCAS, see Table 2.

Table 2. Areas covered in Velikova’s Content Analysis System

<table>
<thead>
<tr>
<th>Velikova’s Content Analysis System</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Symptoms (EORTC-QLQ-C30)</strong></td>
</tr>
<tr>
<td>Pain /ache only</td>
</tr>
<tr>
<td>Appetite</td>
</tr>
<tr>
<td>Fatigue</td>
</tr>
<tr>
<td>Nausea</td>
</tr>
<tr>
<td>Sleep</td>
</tr>
<tr>
<td>Dyspnoea</td>
</tr>
<tr>
<td>Bowel symptoms</td>
</tr>
<tr>
<td>Other symptoms</td>
</tr>
<tr>
<td>(1-8 not specified)*</td>
</tr>
<tr>
<td><strong>Clinical decision-making</strong></td>
</tr>
<tr>
<td>Type of consultation</td>
</tr>
<tr>
<td>Evaluative consultation</td>
</tr>
<tr>
<td>Psychotropic drugs</td>
</tr>
<tr>
<td>Cancer treatment 1-3</td>
</tr>
<tr>
<td>Supportive treatment</td>
</tr>
<tr>
<td>Referral</td>
</tr>
<tr>
<td>Other advice</td>
</tr>
<tr>
<td>No action, observe</td>
</tr>
<tr>
<td><strong>Functions (EORTC-QLQ-C30)</strong></td>
</tr>
<tr>
<td>Physical</td>
</tr>
<tr>
<td>Role</td>
</tr>
<tr>
<td>Emotional</td>
</tr>
<tr>
<td>Social</td>
</tr>
<tr>
<td>Cognitive</td>
</tr>
<tr>
<td>Sexual</td>
</tr>
<tr>
<td>Overall health</td>
</tr>
<tr>
<td>Financial</td>
</tr>
<tr>
<td><strong>Other topics</strong></td>
</tr>
<tr>
<td>Cancer-related worries</td>
</tr>
<tr>
<td>Info on cancer treatment</td>
</tr>
<tr>
<td>Info on cancer course/prognosis</td>
</tr>
<tr>
<td>Info on tests</td>
</tr>
<tr>
<td>Info on symptoms/side effects</td>
</tr>
<tr>
<td>Refer quality of life area</td>
</tr>
<tr>
<td>(1-6, not specified)*</td>
</tr>
</tbody>
</table>

*VCAS has the opportunity to code for up to 8 other, non-pre-specified symptoms and HRQoL-areas, who initiated the topic, and whether the topic was mentioned or discussed.
VCAS characterizes the content of communication concerning symptoms, side effects, functional issues, and medical decision making. The analysis includes listening to audio-taped consultations and coding for topics discussed, who initiated them, and whether the topic was mentioned or discussed. Furthermore, as VCAS does not evaluate how information is given, and as the communication is not separated into small units, the assessment is less time-consuming. Because of VCAS’s relative simplicity it cannot be used for analyzing details in the consultations such as the amount of open-ended questions or number of emotional signals coming from the patient in the same way as IAS can. However, it may be an adequate and time-effective way of quantifying and evaluating patient–physician communication in large studies, where focus is on the consultations’ content.

**Method triangulation evaluating communication**

Compare results from different methods (self-reported contra observational) and perspectives (patient, physician, and observer) for measuring communication, i.e. method triangulation, can be used to explore possible differences in perceptions of communication. Method triangulation provides important information when choosing method for assessing communication and when evaluating results from research using different methods or perspectives.

There is relatively little known about how different methods and perspectives correlate. Agreement between medical records and patient self-reports has shown to be generally good for areas with little ambiguity such as medication use (151), prescription, test ordering, or referrals (152). However, correlation has been lower for areas requiring interpretation, such as having received counseling (151). Poor correlations have been found between different observational instruments claiming to measure the same communication construct on the same data set (like patient-centered communication and shared decision-making) (4, 153), implying low convergent validity. One study has found reasonably close agreement between patients and observers regarding the frequency with which HRQoL topics are discussed during outpatient oncology visits (154).

The level of agreement between different perspectives has been researched, looking at correlation of self-reports, medical records, and observation in settings other than oncology (138). Furthermore, many communication analysis instruments have not been validated, and few instruments have been directly compared with other instruments designed to assess patient-physician interaction (137).
Need for further knowledge

Given this background, some issues emerge that need further research. The aspects chosen for this thesis concern the character of communication during routine consultations, barriers against psychosocial communication, and possible methods for evaluating communication in oncology care.

Describing the oncology consultations content by qualitatively assessing real consultations would disclose the array of areas that are discussed, and provide in-depth knowledge about the character of the discussions. It could also shed light on what is often not discussed. Knowledge about what characterizes patient-physician communication from the perspective of patients, physicians, and independent observers is potentially important to be able to target specific areas for possible improvements. In addition, few studies have explored the patient-physician communication in the Swedish oncology setting, which may deviate from that in other countries due to possible differences with regard to culture and healthcare systems.

Because previous research has shown that psychosocial issues might be inadequately discussed during the consultations, it would be useful to further explore possible reasons for this. Potential barriers against psychosocial communication have been suggested (110), but no empirical studies have specifically focused on oncologists’ perceptions regarding barriers of psychosocial communication in oncology care. Consequently, knowledge is lacking regarding how prevalent experiences of different barriers are as is knowledge on their potential impact on clinical practice. Exploring oncologists’ perception regarding barriers against psychosocial communication may help to explain the poor effects of psychosocial care interventions in clinical practice (155). Such knowledge could also be used to inform modifications of existing interventions by removing or reducing the most prevalent and clinically relevant barriers, as could the development of new interventions in healthcare organizations.

When evaluating communication in an intervention study, the methods for assessment need to be valid, reliable, and feasible. Instruments and measures for evaluating communication in the oncology setting have primarily been based on and developed from theories and hypotheses about the character of patient-physician communication (144, 145, 148). This fact could cause some areas to be missed, possibly leading to non-valid instruments that are unable to measure all content. To describe the content of the consultation by qualitatively assessing real consultations might disclose more areas and give deeper understanding of areas discussed. This information could be used to evaluate the coverage of, and possibly further develop already existing instruments, and could also provide information for the development of new ones.
Method triangulation and looking at the concordance of methods and perspectives can be helpful in deciding the most appropriate and feasible method or combination of methods, in relation to a specific research question. Method triangulation and comparison of communication analysis instruments have so far been largely missing from the scientific literature.
Aims

The overall aim was to explore the character of patient-physician communication in Swedish oncology outpatient care, and to contribute to the understanding of how to effectively assess patient-physician communication in this setting.

The specific aims were:

- To characterize the content of Swedish patient-physician communication in oncology care, by using both a qualitative approach (Paper I) and a quantitative approach where a structured analysis system is used in combination with a global scale (Paper III). The aim was also to assess the quality of communication from the perspectives of patients, physicians, and observers.

- To explore oncologists’ perceptions of barriers against discussing psychosocial issues with patients during consultations, and the clinical relevance of different barriers. In addition, one aim was to assess oncologists’ psychosocial orientation (Paper IV).

- To evaluate different methods for patient-physician communication assessment in oncology care with the primary aim of detecting changes in content during routine consultations after an intervention (Papers I, II, III). Another aim was to determine the agreement level between different perspectives (patient, physician, and observer) used for evaluating communication (Paper III).
Study setting

Research studies aiming to evaluate real-life human behavior have to be done in a real-life setting. The setting in which the research is done will affect the results. The perception of a severe disease such as cancer differs between cultures and countries. Also, the oncology practice and the way in which care and treatment are organized and delivered vary around the world and may also differ between hospitals or clinics in the same country. Differences can be found in areas like the healthcare organization and the role and responsibility of different professions caring for patients with cancer. Below is a description of the setting in which the studies in this thesis have been made.

The Swedish oncology setting

In Sweden, the 20 regional county councils, in practice, almost exclusively manage all cancer care. All surgery for cancer is done at regular surgical departments at the hospitals, whereas radiation and medical treatment are done at special oncology departments, usually one in each county. In Sweden there are no specialized cancer hospitals as there are in other parts of Europe and in the USA. The Swedish cancer care is characterized by multidisciplinary cooperation, and many patients are discussed in multidisciplinary team (MDT) conferences prior to decisions about further investigations or treatments.

In Sweden oncologists working in the oncology departments are clinical oncologists (combined medical and radiation oncologists). Many of the oncologists, particularly those working at the larger university/regional hospitals have a sub-speciality in one or a few specific cancer diagnoses, or in a few cases a specific treatment. In general, at least in the county hospitals, oncologists treat all or most types of cancer in the various stages.

Six Regional Cancer Centers (RCC), have the responsibility for the cancer care after a governmental decision based upon an official investigation completed in 2009 (156). The RCCs coordinate and organize the cancer care in each healthcare region, most of which consist of several county council are-
as/regions. The RCC is responsible for publishing national or regional care programs defining investigations, treatments, and follow-up of the various diagnoses. They are also responsible for organizing quality registries in which the quality of different interventions can be assessed. The registries are also a rich source of research material. Recent findings show that the oncology care in Sweden is highly efficient in an international perspective, with high cancer survival rates (157).

The oncological healthcare chain
The diagnosis of cancer is generally made by a surgeon after a referral from a general practitioner, but this varies extensively between diagnoses and specific cases. When a cancer is diagnosed the patient is often referred to the oncology department for radiation or medical treatment and general care. The oncological treatment can be given before or after surgery, or done alone, with the purpose of curing or prolonging the life of the patient. Most patients referred to the oncology departments are discussed in MDT conferences involving surgeons, radiologists, oncologists, nurses, and other specialized personnel. Today, patients with cancer should have a special “contactnurse” whom they can contact with their questions and concerns (156).

After treatment, follow-up is done by the oncologist, a surgeon, or a general practitioner, depending on the type of cancer and prognosis. Most patients with incurable cancer are taken care of by the oncology teams and are given different palliative treatments like chemotherapy or radiotherapy to prolong life expectancy and interrupt the disease progression. In the end-of-life period, many hospitals or communities, often in collaboration, have organized specialized palliative care teams or clinics (158).

Consultations at the Swedish oncology department
Most of the care at the oncology departments is done on an outpatient basis in which the patient comes to the department and goes home the same day. The outpatient visits can either be a visit to a physician for consultation only (such as information about diagnosis, treatment decision, response evaluation, or follow-up) or in connection with a specific treatment like chemotherapy (e.g. for evaluation of toxicity or response).

If necessary, the patient is cared for in a ward. Inpatient care has become much less common in recent decades and these visits are usually as short as possible (one or a few days) due to economic constraints. As the inpatient care has become much less common, the outpatient consultations have become more complex. They necessitate much information exchange and treatment decisions, together with the general care of the patients including
drug prescriptions and writing various certificates. Many consultations contain information about clinical trials or follow-up of trial interventions, requiring more time than a consultation without specific research activities. However, these consultations are not routinely booked for longer visits.

In Sweden, the first consultation with a patient at the oncology department is generally longer, often 40 minutes. Other routine visits to the department are generally booked for 20-30 minutes, but this varies between hospitals and diagnoses. When called to a medical visit to the oncology department, patients are encouraged to bring a relative or friend, which many patients do. The patient usually sees only one physician at each consultation; joint consultations are uncommon. It is also extremely uncommon that a patient is first seen by a junior doctor and then only briefly by a more senior consultant, a routine that is practiced in many other countries. In Sweden, patients often have to see different oncologists during their treatment period due to the limited number of oncologists available. At the university hospitals it is not unusual that medical students attend consultations as part of their education.

Gastrointestinal cancer

Papers I-III include adult patients (≥ 18 years) with GI cancer. GI cancer is one of the largest cancer diagnosis groups, and affects both men and women. The diagnosis often has a poor prognosis and is often associated with a great variety of problems and symptoms (22, 159). GI cancer includes colorectal, anal, pancreatic, gastric, small bowel, and hepato-biliary cancers. The majority of the cancers (more than 95%) are adenocarcinomas. Most anal cancers are squamous cell cancers. Surgery is the main treatment (except in anal cancer) although other treatments are often given as well, before or after surgery or alone (159).

The most common type of GI cancer is colorectal cancer, which is the third most common cancer diagnosis among both women and men in Sweden. About 6000 individuals are diagnosed with the disease yearly. The prognosis is generally good and it can be expected that about 60% of the patients will be alive at five years. Colon and rectum cancers have about the same 5-year survival rates, although prognosis is stage-dependent. In stage I (cancers are localized to the bowel wall), about 90% are alive after 5 years, whereas in stage IV, where the cancer is disseminated to other organs, less than 5-10% are alive after 5 years. About 900 individuals are diagnosed with pancreatic cancer in Sweden yearly. Pancreatic cancer is often discovered at a late stage and therefore the prognosis is poor, and survival after 5 years is only about 1% (25). The prognoses for the remaining cancer types vary, but are general-
ly rather poor. GI cancers constitute less than every fifth cancer but are responsible for more than every third cancer death in Sweden (25).

The life expectancy varies and depends on the type of GI cancer, stage of the disease, and a number of prognostic factors. These factors also decide which treatments can be offered, including surgery, chemotherapy, radiotherapy, and more recently, antibody treatments (159). Best supportive care (BSC) should be provided in connection with all treatments but is frequently the only option due to lack of sufficiently efficient anti-tumor-controlling therapies. BSC contains a number of interventions to relieve or prevent all types of problems (physical, mental, social, and existential) that patients with cancer can have.
Methods

If we knew what it was we were doing, it would not be called research, would it?” (Albert Einstein 1879-1855)

The focus of this thesis is to explore the character of patient-physician consultations at the oncology department, explore barriers against psychosocial communication, and evaluate ways for measuring such communication. The methods used to evaluate these aspects have been chosen to answer the present research questions and apply both quantitative and qualitative methods (160).

The main data collection method used is non-participant observation of audio recordings of medical outpatient consultations in the oncology department (Paper I-III). This thesis also applies patient and oncologist self-reported questionnaires (Paper III), medical records audits (Paper II), and a nationwide survey of all clinically active oncologists in Sweden (Paper IV).

Papers I, II, and III are based on material collected as a historical control group in a large randomized controlled trial, with the main objective evaluating the effects of two different HRQoL/QoL instruments in clinical oncology practice. The aim of the historical control group was to evaluate the care, treatment and communication before the intervention, thus reflecting standard care in this setting.

GI cancer was chosen as the study population in Papers I-III, as it is one of the largest cancer diagnosis groups, affecting both men and women. It was also chosen because the disease often has a poor prognosis and is associated with a great variety of problems and symptoms in addition to logistic and convenience reasons. Patients for Papers I, II, and III were collected from two large hospitals in the middle of Sweden.

In the nationwide survey (Paper IV) all clinically active oncologists in Sweden were included. Table 3 contains a methodological summary of the papers presented in this thesis.
Table 3. Methodological overview of the papers

<table>
<thead>
<tr>
<th>Paper</th>
<th>Study population</th>
<th>Data collection</th>
<th>Data analysis</th>
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</thead>
<tbody>
<tr>
<td>I</td>
<td>Patients with GI cancer (n=25), and clinical oncologist (n=6)</td>
<td>Audio recordings of patient-physician consultations from two oncology departments</td>
<td>Qualitative content analysis and estimation of time spent on discussing different topics</td>
</tr>
<tr>
<td>II</td>
<td>Patients with GI cancer (n=61) and clinical oncologists (n=8) and observers (n=2)</td>
<td>Audio recordings of patient-physician consultations from two oncology departments</td>
<td>Content and communication analysis with VCAS and MIPS global scale. Inter-rater agreement analysis</td>
</tr>
<tr>
<td>III</td>
<td>Patients with GI cancer (n=60) and clinical oncologists (n=8), and observer (n=1)</td>
<td>Audio recordings of patient-physician consultations and patient and physician self-reported questionnaires</td>
<td>Descriptive statistics. Statistical comparison of communication quality perception using linear mixed model statistics. Percentage agreement.</td>
</tr>
<tr>
<td>IV</td>
<td>All clinically practicing clinical oncologists in Sweden (respondents, n=344, response rate 64%)</td>
<td>Nationwide postal survey</td>
<td>Descriptive statistics, Cronbach’s alpha, Spearman’s rank order correlation and Stepwise ANOVA</td>
</tr>
</tbody>
</table>

Data Collection

Patient-oncologist consultations (Paper I-III)

The routine patient-physician consultations have been the foundation for Papers I-III. The inclusion of patients was made in two steps, the first between May-June 2005, and the second between March-May 2006. Paper I included 25 consultations (the first inclusion phase). Paper II and III are based on the total historical control group (including both phases, n=70). The inclusion of patients was consecutive and made in collaboration with the practicing oncologists and nurses at the clinic. Patients fulfilling the inclusion criteria were identified in advance to the consultation. All patients included were diagnosed with GI cancer; all stages of disease and all sorts of treatments were eligible. Inclusion criteria for patients were ≥ 18 years,
enough command over the Swedish language to complete an interview/questionnaire, an adequate cognitive status and a survival prognosis of at least four months (as assessed by the treating oncologist). The survival time was based on this group being a historical control group in a larger intervention study that had a duration of four months.

Eligible patients were informed of the study by a letter of invitation and a brief description about the study by the research assistant. At the beginning of the consultation, the oncologist asked if the patient wanted to participate in the study or not. If the patient agreed, an informed consent form was signed and the consultation was audio-recorded.

Six oncologists were included in Paper I, and eight oncologists were included in Papers II and III. All participating oncologists were clinical oncologists regularly seeing patients with GI cancer. Participation was voluntary, however none of the oncologists declined. Two of the participating physicians were resident physicians. Two female oncologists participated in Paper I and three female oncologists participated in Papers II and III. Three male oncologists from one of the two hospitals participated in the majority of the consultations.

Communication content and quality questionnaire (Paper III)
After the medical consultations, both patients and physicians were given self-report questionnaires assessing different aspects, including communication quality and questions regarding which areas had been discussed during the consultation. Both the patient and the physician questionnaires included a Perceived Quality of Communication Visual Analogue Scale (PQC-VAS), where the participants rated their own perceptions of the overall communication quality, ranging from very bad (0) to very good (100). Both the patient and the physician were asked to fill out the questionnaires immediately post-consultation.

Medical records – Medical decision making (Paper II)
Medical records were assessed to gather patient specific information in Paper I, II, and III, like age, gender, diagnosis, and current treatment. In Paper II information about medical decision making for analysis in VCAS was collected from the medical records, according to the manual.

Oncologist Survey-Barrier Questionnaire (Paper IV)
A nationwide, self-reported postal questionnaire evaluating oncologists’ psychosocial orientation and barriers against psychosocial communication
was sent out in November-December 2011 to all clinically active oncologists in Sweden (n=592). Addresses were collected from the national records of healthcare personnel. Of the initially identified oncologists, 50 were not clinically active, and a further five questionnaires were returned due to incorrect addresses. Consequently, the number of eligible oncologists was 537.

The questionnaire included questions on clinician characteristics and the “Physicians Psychosocial Beliefs Scale” (PPBS), which measures physicians’ psychosocial orientation (7). PPBS consists of 32 items and gives a score ranging from 32 (maximum psychosocial orientation) to 160 (minimum psychosocial orientation) (7). The PPBS version adapted by Jenkins and Fallowfield (118) was used. The questionnaire included 11 questions regarding barriers based on a previously published summary of potential barriers against psychosocial communication (110). The questions were developed by the authors and included both whether the specific barrier was perceived and if so, to what extent the perceived barrier affected the oncologists’ clinical practice. The prevalence of barriers perceived is interesting from the perspective of oncologists’ total burden, since handling all barriers require effort and energy. In contrast, the barriers impacting clinical practice might be the ones which directly affect communication negatively.

Before the distribution, the questionnaire was tested on a small group of oncologists (n=8) using think-aloud methodology to improve question clarity, relevance, and coverage (161).

Data preparation and analysis

Communication analysis (Papers I-III)

Qualitative content analysis
In Paper I, the recorded consultations were transcribed verbatim and a qualitative content analysis was carried out independently by two coders. Data analysis started with familiarization of data by reading and listening to all consultations taking notes. Next, preliminary encoding of all text units was done. This was followed by a consensus discussion. Then a more detailed analysis of the data was conducted, using the NVIVO analysis software, which helps the coder to handle and organize the codings and categories made. The emergent categories and sub-categories (in Paper I referred to as categories and themes interchangeably) were further redefined and hierarchically organized through further consensus discussions. A final consensus
meeting was held, deciding on a final description of categories and subcategories describing the content of the consultations.

**Quantitative Communication analysis**

In Papers II and III quantitative communication analyses were done using VCAS and MIPS global scales. These instruments were chosen because the combination of them could give valuable information in the planned larger intervention study, at the same time as they were thought to be feasible for this purpose.

The manuals and information of usage were obtained for each instrument in collaboration with each developer. Each instrument was translated and adapted to the Swedish context by adding relevant examples and definitions in Swedish. For MIPS global scale each of the aspects assessed were defined in the Swedish manual. The manuals were continuously updated throughout the study in connection with consensus discussions held to resolve coding difficulties/conflicts.

The coding of VCAS was directly entered to a work sheet into Microsoft Access while listening to the consultation. During the first listening, the main coding was made; the second listening was mainly to check the initial coding. As the coder heard a topic brought up, the coder noted who initiated the topic and whether it was mentioned or discussed. An area was regarded as being discussed if it contained four or more utterances; if less it was coded as mentioned. Double-coding was allowed, i.e. content could be classified in one or more VCAS-categories. If a coder was uncertain about how to code an area the concern were documented and discussed at a consensus meeting.

The consensus meetings were held continuously during the coding process. The meetings resulted in consensus of how to code and, occasionally, also an update of the manual. Following this, resolved coding difficulties were re-coded according to the consensus decision. All consultations were first coded using VCAS and then using the MIPS global scale.

Coding of medical decisions (such as initiation or interruption of anti-tumor treatments, dose reductions, and supportive care activities) was done after listening to the consultation. In addition, the patients’ medical records were read, which could confirm and/or specify the medical decisions made during the consultation. This was done according to the coding instructions provided by the developers of VCAS.

Coding of MIPS global scale was based on a paper questionnaire (145). Each global concept was judged by the raters on a 4-grade scale where 1=not at all and 5= very. The global ratings included evaluating both the patient’s and
the physician’s behavior during the consultation. An overall judgment of the communication was also made. The general interview rating of “satisfaction with communication” was excluded from the analysis as we did not understand how that could be assessed from an observer perspective.

Feasibility test of VCAS and MIPS global scales (Paper II)
To assess the feasibility of these scales, the duration of the consultations and the coding time of each consultation were assessed. It was also determined whether all the content could be classified according to the systems and if coding conflicts occurred. In addition the coders documented whether any categories were rarely or never used.

Observer judgment of communication quality (Paper III)
The observer evaluated the overall communication quality per consultation based on the same global scale (PQC-VAS, 0-100) as the patient and physician did in their self-reported questionnaire. These analyses were made at a different time point than the previously described communication analyses. The judgment included evaluating the exchange of information, response to emotional signals, management of uncertainties, decision making, and enabling patient self-management. Different aspects obviously vary in importance between consultations, which is why no standard set of criteria was developed. Instead a context-sensitive perspective was applied, meaning that the observer based judgment on the same overall criteria, but individualized it by taking into account the specific consultation and the issues that seemed important to the individual patient based on patients’ verbal cues. Aspects also affecting judgment were the physicians’ evaluations of the patients’ needs, how they discussed the patients’ problems, and how they took patients’ wishes into account in decisions concerning treatment and care.

Time analysis of consultations (Paper I)
A crude analysis of the proportion of time spent on discussing different topics during the consultation was conducted in Paper I. The analysis was based on three wide-ranging themes: “medical and physical aspects”, “patient-centered aspects” and “other aspects of communication”. The “medical and physical” theme included discussions of diagnosis, treatment, and prognosis. The patient-centered theme primarily included psychosocial aspects including psychological, emotional and social functioning and expressions of concerns and feelings. The category also contained the impact of side effects and treatment on patients’ lives. Because the three themes were mutually exclusive, in discussions regarding issues that could be referred to more than one theme, the patient-centered theme had priority. For instance, a discussion concerning how one side effect from treatment affected a patient’s social function was assessed as “patient-centered area” and not as a “medical
and physical aspect”. The “other aspects of communication” category included polite phrases, jokes, and pauses.

Nationwide survey - Physician questionnaire (Paper IV)
All data from the questionnaires were entered into SPSS version 20, and checked for errors by double-checking the answers in the questionnaires against the data compiled in SPSS. For analysis of perceived barriers the response options “totally agree” and “agree to some extent” were combined and interpreted as agreement to perceiving that barrier. Non-respondents to barrier questions were coded as not perceiving the barrier. Only if the respondent perceived a barrier was he/she asked about the barrier’s impact on clinical practice.

Statistical analyses

Reliability analyses (Papers II and I)
Inter-rater reliability concerns the degree of consistency or agreement on the same phenomenon that exists across multiple coders. Different coders may code a consultation differently; thus, there is a risk for systematic bias if relying on one coder only. Inter-rater reliability using Cohen’s kappa was calculated for the areas measured by VCAS. A weighted kappa was calculated for areas in MIPS global scale as it contains categorical data where the categories are not equal.

Good inter-rater reliability was set at 0.60-0.75, and above 0.75 was regarded as excellent (161, 162). Cohen’s kappa was calculated for all “symptoms”, “functions”, and “information on topics” in VCAS. It was also calculated for specific topics being mentioned or discussed, and for who initiated the discussion.

In the time analysis made in Paper I a confirmability check was carried out by calculating Cronbach’s alpha for “medical and physical aspects”, “patient-centered aspects” and for “other aspects of communication”, respectively.

Statistical comparison of communication quality perception (Paper III)
The ratings on the PQC-VAS from patient, physician, and observer assessments were compared, using linear mixed model statistics for measuring differences in mean values. This statistical method was used because the groups were not independent. The results are presented as model-based mean values with a 95% confidence interval. A p-value less than 0.05 were considered statistically significant. Perspective (patient, physician, and observer)
was considered a fixed factor in the mixed model analysis, while study number and rater ID (the individual physicians’ and patients’ etc.) were considered random factors.

**Agreement on content of consultation among different perspectives (Paper III)**

Percentage agreement for whether emotional functioning was discussed or not during the consultations was calculated between patient, physician, and observer ratings. For these comparisons, response options in the physician questionnaire were collapsed into dichotomous values (Yes= “Yes, very much” and “Yes, partly”. No= “No, not specifically”, “Not at all” and “Was not discussed”)

**Internal consistency of the PPBS (Paper IV)**

To measure the internal consistency of the PPBS, Cronbach’s alpha was calculated.

**Perceived barriers and psychosocial orientation (Paper IV)**

Descriptive statistics were used to describe the character of the oncologists’ perception of barriers against psychosocial communication. Mean scores, ranges, and confidence intervals (CI) were calculated.

Stepwise ANOVA using Akaike Information Criterion (AIC) to select the most appropriate models was used to determine what factors contributed the most to the PPBS scores and perceived barriers/barriers affecting clinical practice. To determine between group differences, Post-hoc, the Bonferroni correction was used to counteract the problem of multiple comparisons. To determine the effect sizes, adjusted $R^2$ for the total model, and partial Eta squared ($\eta^2$) for the individual factors, were used. A p-value of less than 0.05 was considered statistically significant in all analyses.

**Correlation between PPBS and number of perceived barriers**

A Spearman rank order correlation was used to determine the relationship between the PPBS scores, the number of perceived barriers, and the number of perceived barriers affecting clinical practice.
Ethical considerations

Patients diagnosed with cancer and their families are in a vulnerable position as they are in great need of medical help. Respect and consideration were shown to all patients and to their relatives by those who worked with the inclusion of patients. Patients included were invited in person at the clinic. All patients were informed that they were free not to participate in the study. The patients were also informed both orally and in writing of the study’s aim, procedures, and rights to at any time discontinue their participation in the study. All patients who were included in the study (the historical control group, Papers I-III) filled out informed consent forms. A few patients who were emotionally unable to complete the questionnaire directly after the medical visit, but who really wanted to participate in the study, were allowed to take the questionnaire home and return it by mail.

Oncologists’ answers to the self-report questionnaire and the national survey have been handled confidentially, and participation in the studies included in this thesis has been voluntary.

All presented data has been anonymized. All patient/oncologist personal identifiers have been removed or edited so the patients/oncologists described are not identifiable through the details of this thesis.

All studies were submitted to the regional ethic committee and have received advisory statements (In Swedish terms=Rådgivande yttrande) (Papers I-III; Dnr 2005-024 and Paper IV; Dnr 2011-124).
Results

Communication works for those who work at it
John Powell (1963-)

Below are the main results from the papers included in this thesis. Some additional results concerning the character of the consultations that have not been reported in Paper III have been included here.

The character of the oncology consultations
The patient-physician communication was assessed both qualitatively (Paper I) and quantitatively (Paper III) to provide an in-depth description of the character in terms of content, depth of discussions, and who most often initiated the discussion of different topics. The results from the different approaches are summarized below.

Qualitative characterization
The patient-physician consultations content can be described by the following seven main content categories; “Disease and treatment”, “Healthcare planning”, “Psychological wellbeing”, “Everyday living”, “Coping with disease”, “Expressions of concerns and feelings” and “Other aspects of communication” (Paper I).

Physical and disease related issues
The disease and treatment were the main subjects in the consultations. Symptoms of the disease and side effects of treatments were often discussed. Furthermore, issues, such as patients’ medical histories, general condition, weight, appetite, and activity, were also often discussed.

Cancer treatments were discussed in numerous contexts, including available treatments, aim of treatments, pros and cons of treatments, treatment regimens, and expected treatment results. Sometimes the physicians discouraged patients’ treatment suggestions because of poor evidence bases. Clinical trials were discussed with eligible patients and study protocols were checked to adjust patients’ treatments when side effects occurred.
Pharmaceutical treatments aiming at relieving side effects or easing symptoms were also discussed, as were treatments of other diseases. In some cases treatment adherence was addressed.

In some consultations physicians informed patients with incurable cancer about the home healthcare team as a possibility for getting specialized palliative care at home.

In many of the consultations some kind of healthcare planning was included, such as general treatment plans (start and end of treatment), referrals, sick leave, and drug prescriptions. Date and time for the next visit were often mentioned at the end of the consultation.

**Psychosocial discussions**

Psychosocial issues were discussed in some of the consultations. These discussions included the effects of the disease and its treatment on patients’ emotional and social functioning. Problems like insomnia, fears of relapse and death, and difficulties concentrating and relaxing were discussed. Some patients’ described how their frame of mind had changed since the diagnosis. Other patients expressed that they were depressed, or felt emotionally fatigued and lethargic or experienced decreased self-confidence after being diagnosed with cancer. Some patients were socially active, while others had withdrawn from social activities due to symptoms or side effects.

Topics relating to “Patients’ daily lives” included discussions about work, housing, and other aspects of physical functioning and self-efficacy (e.g. getting dressed) were discussed in some consultations. Living environment and the ability to be active in leisure activities were also occasionally discussed. Issues concerning the patient’s QoL were seldom explicitly mentioned, but were likely to be part of other areas discussed during the consultations, such as family, health and symptom control, leisure activities, and self-management.

In some consultations the patients’ way of coping with the disease was discussed. These discussions included how the patients had come to accept the disease and how to handle the situation in the best possible way. Furthermore, relatives’ and friends’ coping were occasionally discussed, as was the support they offered the patient. Fears and emotions were also discussed, and for some patients help with referrals to a counselor was offered.

**Intra-relationship connected content**

In some consultations the physicians conveyed care and support to the patients and expressed understanding and empathy for the patients, for instance accommodating the patients by adjusting the treatment and examination plans to the patient’s wishes. Some physicians reassured patients that they
were going to do all they could to help the patients and stressed the importance of not giving up.

Patients’ and relatives’ trust and hope in the physicians were conveyed verbally in some of the consultations. Further, some patients expressed that they would endure whatever treatment would give them a better chance of being permanently cured.

Some patients expressed anger and critique of how physicians encountered previously had communicated. All kinds of misunderstandings were also discussed, including misunderstandings concerning the aim of the treatment (curative/palliative), the planning of the treatment, and severe side effects. Misunderstandings concerning pharmaceutical treatments, including dosage and/or indication were also discovered and discussed in some consultations.

**Other and non-content aspects of communication**
Friendly and causal remarks and social aspects of communication like talk about the weather, polite phrases, greetings, and jokes were also common in these consultations. Polite phrases were often placed in the beginning and at the end of the consultations.

**Quantitative characterization**
The results from the content analysis showed that the most common areas for discussion during the consultations were overall health, bowel symptoms, and pain; the two latter are common symptoms in GI cancer (see Table 4). These areas were discussed in 83-90% of the consultations. Overall health and pain were the only topics where the physician dominated the initiative for discussion. For other categories the initiative was either equal or mostly patient-initiated. Relatives rarely initiated any topics (4%). Information on tests, cancer treatment, cancer prognosis, and side effects and/or symptoms were covered in ≥ 87% of the consultations. Role functioning and physical functioning were discussed in ≥ 75% of the consultations.
Table 4. Results from the observational analyses of the content of the consultations

<table>
<thead>
<tr>
<th>Content area</th>
<th>Number (d/m)*</th>
<th>Discussed/mentioned in (%) of the consultations</th>
<th>Initiated the topic (d/p/r)** (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall health</td>
<td>54 (36/18)</td>
<td>90</td>
<td>43/10/1</td>
</tr>
<tr>
<td>Bowel symptoms</td>
<td>51 (40/11)</td>
<td>85</td>
<td>17/32/2</td>
</tr>
<tr>
<td>Pain</td>
<td>50 (42/8)</td>
<td>83</td>
<td>26/22/2</td>
</tr>
<tr>
<td>Role functioning</td>
<td>46 (35/11)</td>
<td>77</td>
<td>18/29/0</td>
</tr>
<tr>
<td>Physical functioning</td>
<td>45 (35/10)</td>
<td>75</td>
<td>14/31/0</td>
</tr>
<tr>
<td>Appetite</td>
<td>41 (30/11)</td>
<td>68</td>
<td>15/24/2</td>
</tr>
<tr>
<td>Emotional functioning</td>
<td>38 (26/12)</td>
<td>63</td>
<td>6/27/5</td>
</tr>
<tr>
<td>Fatigue</td>
<td>34 (20/14)</td>
<td>57</td>
<td>11/22/1</td>
</tr>
<tr>
<td>Social functioning</td>
<td>32 (18/14)</td>
<td>53</td>
<td>13/19/0</td>
</tr>
<tr>
<td>Sleep</td>
<td>25 (11/14)</td>
<td>42</td>
<td>9/15/1</td>
</tr>
<tr>
<td>Nausea</td>
<td>23 (13/10)</td>
<td>38</td>
<td>10/12/1</td>
</tr>
<tr>
<td>Cognitive functioning</td>
<td>10 (5/5)</td>
<td>17</td>
<td>2/7/1</td>
</tr>
<tr>
<td>Dyspnoea</td>
<td>6 (3/3)</td>
<td>10</td>
<td>2/3/1</td>
</tr>
<tr>
<td>Sexual functioning</td>
<td>1 (1/0)</td>
<td>2</td>
<td>0/1/0</td>
</tr>
<tr>
<td>Financial situation</td>
<td>1 (0/1)</td>
<td>2</td>
<td>0/1/0</td>
</tr>
</tbody>
</table>

**Topics discussed during consultation**

| Information on tests          | 57 (-/-)      | 95                                              | -                                 |
| Information on cancer treatment| 53 (-/-)     | 88                                              | -                                 |
| Information on cancer progress/prognosis | 52 (-/-)  | 87                                              | -                                 |
| Information on symptoms/side effects | 52 (-/-) | 87                                              | -                                 |
| Cancer-related worries        | 30 (27/3)     | 50                                              | 0/25/5                           |
| Information on coping/emotional| 15 (-/-)    | 25                                              | -                                 |

*Number, d= discussed, m= mentioned. **Initiated the consultation most often, d= doctor, p=patient, r=relative, - = not measured by VCAS.

Furthermore, emotional functioning was discussed in 63% of the consultations. The observations showed that a clear majority (71%) of these discussions were patient-initiated. Discussion of cancer-related worries, life expectancy, end-of-life suffering, and waiting times were covered in 50% of the consultations. Information on coping and emotional issues was covered in 25% of the consultations.

Social function was discussed in 53% of the consultations, most often initiated by patients. Besides cognitive functioning, dyspnoea, sexual functioning, and financial situation were discussed the least in the consultations.
Content of consultations- Patients’ and oncologists’ perceptions

According to the patients’ self-reported content of the consultation, general condition was discussed in all consultations, and disease symptoms and side effects of treatment in most. Emotional functioning, daily activities, and role-functioning were perceived to have been discussed in 48-63% of the consultations. Only 29% of the patients perceived that the disease and treatment effects on social relations had been discussed during the consultation (Table 5).

According to the oncologists’ self-reported content, physical functioning was discussed in all consultations. The oncologists also reported having discussed patients emotional functioning and QoL frequently. In 20% of the consultations, emotional functioning was either not perceived as discussed or poorly discussed, according to the oncologists. The corresponding number was 14% for patients’ overall QoL.

Table 5. Discussed topics according to patient and physician questionnaires.

<table>
<thead>
<tr>
<th>Patient perception of areas discussed</th>
<th>Yes, n (%)</th>
<th>No, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>General condition</td>
<td>49 (100)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Disease symptoms</td>
<td>42 (86)</td>
<td>7 (14)</td>
</tr>
<tr>
<td>Side effects</td>
<td>40 (83)</td>
<td>8 (17)</td>
</tr>
<tr>
<td>Emotional function</td>
<td>30 (63)</td>
<td>18 (38)</td>
</tr>
<tr>
<td>Daily activities</td>
<td>28 (58)</td>
<td>20 (42)</td>
</tr>
<tr>
<td>Role function</td>
<td>23 (48)</td>
<td>25 (52)</td>
</tr>
<tr>
<td>Disease’s effects on relations</td>
<td>14 (29)</td>
<td>34 (71)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Physician perception of ease in discussing the following areas</th>
<th>Yes, very much, n (%)</th>
<th>Yes, partly, n (%)</th>
<th>No not specifically, n (%)</th>
<th>No not at all, n (%)</th>
<th>Was not discussed, n (%)</th>
<th>Not easy to discuss or not discussed at all, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical function</td>
<td>52 (87)</td>
<td>8 (13)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0</td>
</tr>
<tr>
<td>Emotional function</td>
<td>7 (12)</td>
<td>41 (68)</td>
<td>7 (12)</td>
<td>3 (5)</td>
<td>2 (3)</td>
<td>12 (20)</td>
</tr>
<tr>
<td>Quality of life</td>
<td>20 (33)</td>
<td>32 (53)</td>
<td>3 (5)</td>
<td>4 (7)</td>
<td>1 (2)</td>
<td>8 (14)</td>
</tr>
</tbody>
</table>
Time spent on discussing three main themes
The mean time for the consultations was 19 minutes (range 8-36) in Paper I. In Paper II and III the mean length of consultations was 23 minutes (range 4-49 minutes).

Paper I shows that the mean proportion of consultation time spent on discussing “physical and medical” issues was 79%, (range 59-93% of the total time). Psychosocial topics, (in Paper I referred to as “Patient-centered topics”), were discussed in mean 16% of the dispositional consultation time (range 0-41%), while 6% was spent on other aspects of communication (range 0-20%).

Quality of communication
Perception of the quality of communication varied between perspectives, but was quite high for all perspectives. Patients reported the highest communication quality, followed by the physician. The observer rated the communication quality the lowest.

Patients’ perceptions of communication quality on the PQC-VAS had a mean value of 92 (range 47-100, SD 10). Corresponding results from the physicians were 78 (range 34-97, SD 14), and for the observer 71 (range 31-100, SD 20). The patients’ rating of the communication quality differed significantly from both the physicians’ and observers’ mean values (p<0.001 and p=0.004 respectively).

Oncologists’ psychosocial orientation and perceived barriers

Oncologists’ psychosocial orientation
The PPBS revealed excellent internal consistency, with a Cronbach’s alpha of 0.858. The oncologists’ scores of the PPBS, ranged from 49-123; the mean value was 85.5, and SD 13.0. Oncologists considering discussions of psychosocial issues as fairly important had higher PPBS-scores than those who regarded it as very important (p<0.0001), which further supports the validity of the PPBS.

The psychosocial orientation among oncologists was rather homogeneous. Of the factors explored; place of work, age, professional seniority, main country for completion of medical education, and having supplementary education with psychosocial focus was found to impact the PPBS-score, adjusted R²=0.128. Of these, supplementary education with psychosocial
focus (partial $\eta^2=0.04$) and place of work (partial $\eta^2=0.04$) had the strongest effect on the PPBS.

The results showed that older physicians were more psychosocially oriented than younger ($p=0.002$), and those having supplementary education with psychosocial focus were more psychosocially oriented than those without ($p=0.001$). Oncologists working at Hospice, or palliative home care teams, were more psychosocially oriented than those working at University hospitals ($p=0.0001$), and other hospitals ($p=0.002$).

Gender, sub-specialty, and amount of patient contact had no correlations with psychosocial attitudes and beliefs ($p \geq 0.05$).

**Oncologists’ perceptions of barriers against psychosocial communication**

A majority of the oncologists (93%) perceived at least one barrier, and most oncologists (79%) perceived that one or several barriers have some or a large impact on their clinical practice. The oncologists perceived an average of five different barriers and an average of 3.5 barriers impacting clinical practice. There were some differences between the most commonly perceived barriers and the ones impacting clinical practice (Table 6).

The three most frequently perceived barriers affecting clinical practice were “insufficient consultation time”, “lack of resources to handle the potential psychosocial problems discovered”, and “lack of good methods in clinical practice for evaluating patients’ psychosocial health” (Table 6). Of the responding oncologists, one-third perceived that they had insufficient knowledge about how to communicate regarding psychosocial issues with their patients, most of which perceived this affected their clinical practice.

The factors impacting on the amount of perceived barriers were: supplementary education with psychosocial focus, gender, place of work, sub-specialty, and country of education, adjusted $R^2=0.13$. Of these, sub-specialty (partial $\eta^2=0.07$) and supplementary education with psychosocial focus (partial $\eta^2=0.06$), affected the number of perceived barriers the most.

The factors impacting on the amount of perceived barriers affecting clinical practice were: place of work, gender, country of education, and supplementary education with psychosocial focus, adjusted $R^2=0.06$. Of these, supplementary education with psychosocial focus (partial $\eta^2=0.03$) and work place (partial $\eta^2=0.02$) affected the number of perceived barriers affecting clinical practice the most.
Table 6. Oncologists’ perceived barriers in relation to discussing issues of psychosocial character with patients

<table>
<thead>
<tr>
<th>Number perceiving barrier, n (%)</th>
<th>Number perceiving barrier impacting their clinical practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>To a high degree or to some extent</td>
<td>(To a high degree or to some extent) (In relation to those who perceived a problem) In relation to total, 344</td>
</tr>
<tr>
<td>The consultation time is insufficient to discuss psychosocial issues with patients</td>
<td>259 (76%)</td>
</tr>
<tr>
<td>Feedback is lacking on how I practice my profession, regarding patients’ psychosocial health</td>
<td>238 (69%)</td>
</tr>
<tr>
<td>There is a lack of support from the clinic’s leaders (e.g. guidelines and memos) regarding how to handle issues concerning patients’ psychosocial health</td>
<td>198 (58%)</td>
</tr>
<tr>
<td>There is a lack of resources for taking care of the potential psychosocial problems I discover</td>
<td>179 (53%)</td>
</tr>
<tr>
<td>There is a lack of good methods in clinical practice for evaluating patients’ psychosocial health</td>
<td>178 (52%)</td>
</tr>
<tr>
<td>There is a lack of routines for how to address psychosocial issues with patients</td>
<td>159 (46%)</td>
</tr>
<tr>
<td>It is unclear whose responsibility it is to handle patients’ psychosocial health</td>
<td>154 (45%)</td>
</tr>
<tr>
<td>There is a lack of routines for how to act if I discover psychosocial problems</td>
<td>130 (38%)</td>
</tr>
<tr>
<td>I have insufficient knowledge about how to communicate on psychosocial issues with patients</td>
<td>113 (33%)</td>
</tr>
<tr>
<td>There is a lack of support from physician colleagues regarding how to handle issues concerning patients’ psychosocial health</td>
<td>77 (23%)</td>
</tr>
<tr>
<td>It is not the physician’s task to ask patients about their psychosocial health</td>
<td>16 (5%)</td>
</tr>
</tbody>
</table>

Oncologists with supplementary psychosocial education perceived less barriers and barriers affecting clinical practice (p=0.00001, p=0.003 respectively) than those without such education. Female oncologists perceived more barriers and barriers affecting clinical practice than male oncologists (p=0.01, p=0.02 respectively). Oncologists who worked with palliative care perceived fewer barriers than those who worked with many different diagnoses (p=0.0001), malignant lymphoma (p=0.04) and breast cancer (p=0.03). These correlations was not statically significant for barriers affecting clinical practice (p>0.05). Oncologists who had received the major part of the medical training in another country than Sweden perceived more barriers affecting clinical practice (p=0.03), however no such correlation were seen for the total amount of barriers (p>0.05). Oncologists who worked at Hospice or
with palliative home care perceived fewer barriers affecting clinical practice than oncologist working at smaller hospitals (p=0.03).

There were no significant differences in number of perceived barriers impacting clinical practice based on age, amount of patient contact, or professional seniority (p>0.05).

**Correlation between the PPBS and the number of perceived barriers**

There was a weak positive correlation between PPBS-scores and number of perceived barriers ($r_s=0.490$, $p<0.0001$). There was also a weak positive correlation between PPBS-scores and number of barriers affecting clinical practice ($r_s=0.421$, $p<0.0001$). The results indicate that less psychosocially-oriented oncologists perceived more barriers and barriers affecting clinical practice.

**Methods for evaluation of patient-physician communication**

Research indicates that there is a need for improvement of communication in the oncology setting. Interventions made to improve communication need to be evaluated in reliable, valid, and feasible ways. Below the results concerning methods assessed for evaluating communication in the oncology setting is summarized.

**Reliability of VCAS and MIPS global scale**

Reliability was assessed using Cohen’s kappa for the areas measured with VCAS. The results varied, but were mainly good. As shown in Paper II, the mean kappa value for all categories was 0.80. For symptoms the kappa varied between 0.65 and 1, and for the different functions between 0.61 and 1. Cohen’s kappa for categories on “information on topics” varied between 0.20 and 0.87. All categories had kappa values over 0.60, except the “Info on test” category, which had a kappa of 0.20. Inter-rater reliability for “medical decisions” varied between 0.75-1, mean 0.93. All categories in VCAS were coded in one or more consultations. However, a few categories like dyspnoea, sexual functioning, and financial situation were coded only once or a few times in total.

The weighted kappa for MIPS global scale varied between 0.25 and 0.73, mean value 0.42. The categories under “clinician rating” and “significant other ratings” had the lowest kappa values, under 0.40. The categories in “general interview ratings” and “patient ratings” varied between 0.42 and
0.73; the highest inter-rater agreements were obtained for the “psychosocial focus” category.

Feasibility of VCAS and MIPS global scale
The meanings of the words “drowsiness” and “fatigue” cannot be separated sufficiently in the Swedish language and therefore the drowsiness category was excluded, while fatigue was kept in the study. The same problem occurred for the “pain” and “ache” categories, where “pain” was kept, while “ache” was not used.

The time for analysis using VCAS was twice the consultation time plus 1-2 minutes per consultation, which was used for backing the recordings or re-listening to unclear content. Mean time for analysis with MIPS global scale was equivalent to the consultation duration. The coder had then listened to the consultation twice before, coding VCAS.

Coding difficulties with VCAS and MIPS global scale
The coding difficulties were different for VCAS and MIPS global scales. For VCAS, coding difficulties per consultation varied between 1-11 per consultation. The most common coding difficulties from VCAS were whether a subject had been discussed or mentioned, and distinguishing who initiated the topic.

Coding difficulties for MIPS global scale were different as the coders did not experience explicit coding difficulties. However, consensus discussions showed a clear difficulty in how to weigh implicit aspects included in the concepts like “patient-centeredness” or “physician sensitivity” and arrive at a certain score. One coder could implicitly or unconsciously weigh one aspect of communication as more important than the other coder did, which would result in different global judgments being made and reliability accordingly being low.

Outcomes depending on perspective
According to the self-reported questionnaires, the perception of whether or not emotional functioning had been discussed differed depending on perspective. The physicians reported it to be more often discussed than did the patients.

In 41% of the consultations, all perspectives (patients, physicians, and observer) were in agreement on whether emotional functioning had been discussed or not (total agreement). In 15% of the consultations, patients and
physicians perceived emotional functioning as discussed while the observer did not. According to the physicians the topic had been discussed in an additional 22% of the consultations that neither the observer nor patient reported.

Patients rated the communication quality the highest and the observer rated the communication quality the lowest. Patients’ perceptions of communication quality on the PQC-VAS had a mean value of 92 (range 47-100, SD 10). Corresponding results from the physician questionnaire were 78 (range 34-97, SD 14), and for the observer 71 (range 31-100, SD 20).

The patient ratings of communication quality differed significantly from those of both the physicians and observer’s with estimated marginal groups mean values ratings (p<0.001 and p=0.004, respectively).
Discussion

You won’t find a solution by saying there is no problem
(William Rotsler 1926-1997)

This thesis adds to the knowledge about patient-physician communication in terms of describing its content and character, and of exploring oncologists’ psychosocial orientation and perceived barriers against psychosocial communication. In addition, it contributes to the evaluation and development of methods for communication analyses in the oncology setting. The results have both practice and research implications, which are discussed further on.

The character of patient-physician consultations

According to the conceptual framework by Feldman-Stewart et al., the communication between patients and physicians has the purpose of meeting their individual communication goals (66). The communication goals applicable in oncology can be described to incorporate optimal care of the patient with cancer, including attention to the patients’ physical and psychosocial response to the cancer experience (52).

A key finding is that focus during the consultations is on medical care, including disease status and medical decisions. The focus on medical care was shown in terms of time spent discussing these topics (Paper I) as well as the frequencies of these issues being discussed (Paper III). Psychosocial issues are discussed more seldom, and when discussed, it is most often the patients who initiate the discussion. These results are highly coherent with previous research findings from other oncology settings (85, 98, 102, 104, 163).

Discussions concerning psychosocial aspects

Being diagnosed and treated for cancer can cause emotional distress, depression, anxiety, limitations in roles and social activities, as well as problems of existential and financial character. Hence, the psychosocial aspect of the disease and treatment is evident. This thesis reveals that psychosocial issues in outpatient GI oncology consultations are discussed less frequently than the physical aspects of the disease, and sometimes not at all. Social function-
ing was according to the observation analysis, discussed in 53% of the consultations, which concurs with previously reported findings in routine oncology consultations (85, 132). Patients’ emotional functioning was, according to the observation analysis, discussed in 63% of the consultations, which is somewhat more than previous research has shown (85, 104). This fact can indicate that Swedish oncology care is striving towards meeting more patient-centered standards, including psychosocial aspects. When psychosocial issues were discussed, they were in most cases initiated by the patients, in consistency with previous reported findings (85, 163). Furthermore, patients reported high satisfaction with the quality of the communication during the consultations (Paper III). This, combined with the greater amount of patient initiation of both psychosocial and physical topics during the medical consultations, could indicate that the consultations are highly patient-centered. It could also indicate that patients themselves are allowed to set the agendas, and to discuss issues important to them.

Nonetheless, this thesis and other scientific literature indicate that psychosocial issues are not discussed as frequently as suggested appropriate by international consensus guidelines, which in principle state that all consultations should include psychosocial needs assessment (37). Failure to address psychosocial issues during consultations can result in inadequate assessment of such problems, which can lead to needless patient and family suffering, contribute to reduced adherence to prescribed treatment regimens, and potentially affect the course of the disease (97, 164, 165). Consequently, adjustments may be needed to ensure that patients’ psychosocial healthcare needs are being met, not only to improve the social and emotional wellbeing of the patient, but also to optimize the effect of the cancer treatment.

Patients frequently want to discuss psychosocial issues with their oncologist, yet studies show that some patients are hesitant to initiate these topics themselves (84, 85). At the same time, oncologists tend to wait for the patient to initiate psychosocial discussions rather than initiate such discussions themselves (84, 85). As both patients and oncologists might be hesitant to raise these issues it is not surprising that psychosocial issues are not discussed more often. This could result in an increased risk that psychosocial problems go undetected. Patients with cancer may not be aware that some psychosocial problems can be resolved or minimized by healthcare interventions. Therefore the clinicians may need to take greater responsibility for informing patients about psychosocial problems often related to the disease and what local resources are available to relieve them. Furthermore, it might be helpful to clarify that it is acceptable to discuss psychosocial issues during the consultations by routinely ask the patient about these issues.
One psychosocial area that is often forgotten in the oncology setting is sexual functioning. Studies have shown that sexual functioning can be highly affected by cancer and its treatments (22, 34). Sexual functioning is an important element of QoL for many people (166), and can lead to relationship difficulties and emotional problems if disrupted. Maintaining sexual functioning can be a sign of wellbeing and ability to cope with the illness and treatment (167). Despite its importance, Paper III shows that the topic was discussed in only one of the consultations evaluated. These results are confirmed by previous research showing that such discussions during consultations are rare (168, 169). Furthermore, other studies show that there seems to a gender difference, where male patients are often better informed about side effects of cancer and treatment on sexual functioning than female patients are (168). These results combined indicate that sexual functioning may be even more difficult to discuss during a consultation than other psychosocial issues, such as psychological or emotional ones.

Focus on medical and physical aspects

The focus on medical and physical aspects of cancer during the consultations is not surprising nor is it a problem as these aspects are essential in oncological consultations. They are frequently perceived as primary communication goals by both patients and physicians as they inevitably affect patients’ lives and ultimately their survival. Patients’ information needs are to a great extent treatment- and disease-related (99). This means that medical, physical, and psychosocial aspects all can be part of patient-centered care and communication. Many patients with cancer frequently have a short survival time unless actively treated, and a plethora of symptoms. This is particularly true for the group of cancer studied, the GI cancers. If pain or other disabling symptoms are not adequately relieved, the patient is not helped. Because these aspects are discussed to such a great extent, there are prerequisites for high communication quality and patient-centeredness with regard to medical and physical aspects.

Misunderstandings during consultations

Paper I indicated that misunderstandings do occur concerning issues including treatment intention and disease severity. Misunderstandings in oncology consultations are not uncommon and have previously been reported, especially concerning the prognosis and intent of treatment (52, 61-63). Communicating medical information is difficult, and the perception of what has been said can differ depending on the individual’s key attributes, like emotional strain, internal values, and skills (66). Another reason for misunderstandings could be the medical terminology often used in medical encounters (58-60, 170). The results from Paper III indicate that patients and oncologists can have different views about what had been discussed during the consulta-
tions. The differences between perspectives and how the physicians tend to overestimate the amount of psychosocial discussions (85) might also be a source of misunderstandings. Because the perceived messages are what trigger patients’ responses, it is important for the oncologists to control (or confirm) the patients’ understanding of the information given. However, studies have shown that checking up on understanding is one of the least done communication activities during medical oncology consultations (171, 172). In this thesis no conclusions can be drawn on the amount of misunderstandings during consultations, nor of the amount of oncologists checking patients’ understanding of information.

Barriers against psychosocial communication

Studies have previously suggested the existence of barriers against psychosocial communication during oncology consultations (110, 173), and that the physicians’ perspectives have to be explored to detect implementation barriers against psychosocial communication (155). Paper IV is, however, the first empirical study that has explored and quantified oncologists’ perceived barriers against psychosocial communication, showing that 93% of Swedish oncologists perceive one or more barriers in communicating about psychosocial issues with their patients.

The perceived barriers found in Paper IV were associated with individual attributes (like self-perceived lack of knowledge or perceived lack of importance of psychosocial communication) and external, environmental factors (like the organization of care, lack of resources for handling such problems, and too-short consultation time). The results from Paper IV can help explain the poor implementation of results with regard to psychosocial care interventions in clinical practice (174). This knowledge could be used to modify existing interventions and provide information for the development of new interventions in healthcare.

Due to the high prevalence of barriers, it seems as if much may depend on the individual oncologist and patient in determining whether psychosocial problems are discussed or not. Furthermore, many oncologists may experience a conflict between a holistic healthcare approach, the high demands of good medical care, and the restricted resources available. These conflicts in combination with dealing with acutely ill patients, their families, and with emotional issues relating to death and palliative care can cause stress and burnout (175). Previous studies have indicated that a high proportion of oncologists have signs of burnout syndrome (175, 176).
Some oncologists may be faced with too many barriers and too few incitements (110) to routinely discuss patients’ psychosocial health during the consultations. It seems that the oncologist’s own orientation, interest, and knowledge may direct how these issues are discussed and handled, which could contribute to unequal care of patients with cancer. The oncologists’ perceived barriers must therefore be considered in terms of improved support, for instance by improved guidelines, more or improved training, and better follow-up concerning the quality of psychosocial care in oncology.

Measurement and evaluation of communication

Methods for analyzing communication applicable to the oncology setting vary, measuring both or either of the what and how aspects of the communication. Methods also differ regarding perspectives used for analysis, i.e. those of patients, physicians, and observers. The focus in this thesis has been on identifying feasible methods of communication analysis for large study samples where focus has been on what topics were discussed.

Qualitative analysis

By analyzing routine consultations qualitatively, identification of areas being discussed was explored. There has been a lack of qualitative studies reporting on the communication content in oncology. Yet, qualitative methods lend themselves well to exploring the character of the consultations and for evaluating the content validity of existing communication analysis systems. The results from Paper I resulted in suggestions for further development of IAS to fine-tune these instruments’ ability to discriminate between different types of psychosocial topics, including cognitive, social, and sexual functioning. More diversified content categories in IAS could refine the evaluation of communication regarding psychosocial aspects, which could be valuable when assessing specific effects of interventions.

Observational coding of communication

The results showed good to excellent inter-rater reliability for the Swedish version of VCAS, while the inter-rater reliability for the Swedish version of MIPS global scale ranged from fair to good between different items (Paper II). The inter-rater reliability for MIPS global scale received lower inter-rater reliability scores in our study than earlier reported for global scales (145, 147). However, global scales have repeatedly tended to report less inter-rater agreement than IAS (145, 147). One explanation for a generally lower inter-rater reliability for global scales is the nature of the rating, as the global scales are more subjective and unclassifiable by fixed coding rules as they
involve elements of implicit interpretation and judgment by the coder. This can be compared to instruments like IAS or VCAS, developed to objectively code the presence or absence of a communication behavior or topics discussed. Referring to the Feldman-Stewart communication framework described earlier (66), the observer also holds key attributes (skills, values, etc.) just like the patient and oncologist. Consequently, the interpretation of the same consultation can differ and it can be difficult to reach a clear consensus between observers.

As the global scale used in Paper II previously have been reported with higher inter-rater reliability, other possible explanations to the results could be inadequately experienced coders, insufficient training, or the instrument being culturally incompatible. Still, a global measure intuitively gives valuable information offering a holistic evaluation of the communication that otherwise may be lost in the detailed analysis, why further testing and development of these scales is suggested.

In Paper III another global scale (PQC-VAS), was used for evaluating communication quality from patient, physician, and observer perspectives, despite the knowledge about the limited reliability for global scales. The rationale for this was the scientific value of using the same scale from three perspectives allowing method triangulation as well as the method’s feasibility.

Different perspectives on communication

Communication content can be assessed from different perspectives (patient, physician, and observer). The results from Paper III shows that the results may differ depending on method and perspective used for evaluating communication. As all perspectives are more or less affected by the internal key attributes (66), why the same communication may have different meanings to different individuals. There is also a significant difference between the three roles; the patient whose life is depending on a successful treatment, the physician who has much knowledge and experience and has to convey sometimes difficult and/or complicated messages to the patient, and the observer who is not involved in the inter-personal meeting and often misses all messages referring to nonverbal elements like body language but at the same time have full concentration on the spoken communication. These roles may also effect the interpretation of what is being said.

All methods and perspectives have their pros and cons, and careful evaluation of these must be considered when planning and interpreting research. Furthermore, the information from Paper III can also be used in evaluating and comparing results from different studies using different methods or per-
perspectives. Using different perspectives for evaluating communication in research can be recommended because it can provide a more complete picture of reality. The choice of methods should always be based on the research question at hand, the feasibility of the method and the competence of the researchers.

**Thesis results in a theoretical perspective**

The Feldman-Stewart theoretical communication framework (66) can be used to explain many of the findings in this thesis. Papers I and III, which describe the character of patient-physician consultations in terms of content, initiation of topics, and amount of time spent on different topics, are aspects likely to be affected by the four key components in the framework (*communication goals, participants’ attributes, the communication process, and the environment*).

Firstly, the participants’ *communication goals* directs the way in which they communicate, what areas they initiate, and how they respond to questions or cues from the other participant. According to the framework, the participants typically have several primary goals in the consultation and a successful communication helps the participants to work toward their goals. As the goals are what drive the consultation, the goal and enabling goals determine what is discussed during the consultation and what is initiated by respective participant. The reason why oncologists do not initiate psychosocial issues might be that these issues are not always part of their primary communication goals. The same reasons could also be valid for the patient as the patient might not perceive that psychosocial issues are suitable in the medical consultation and therefore does not initiate such discussions.

Secondly, the *participants’ key attributes*, including their values, emotions, and skills, all affect how they communicate and how they interpret communication signals. This also determines what the participants discuss during the consultation. Some patients might be in a crisis reaction due to the disease, which is also likely to affect how they communicate and their ability to receive and remember information from the consultation.

Thirdly, the *communication process*, in which messages are sent, received and interpreted by both participants concurrently. The silent, nonverbal components can be missed in evaluating communication by the means of audio recordings. This limitation could possibly result in the differences seen between observers’, patients’, and oncologists’ perspectives concerning content and quality in Paper III.
Finally, the environment in which the consultation takes place also affects which topics are discussed and who initiates what topic. The initiation of topics during the consultations is likely to be affected by the social frames and expectations on patients and physicians. For example, there is a social expectation of patients to be agreeable, and to collaborate with the attending physician, according to the sick role (31), which could affect what topics the patients initiate.

We found that patients initiated many topics of both physical and psychosocial character. Paper III shows that the different perspectives perceive content and quality of communication differently. These results can be interpreted in relation to the framework, indicating that each participant’s perception is influenced by both the internal and external factors previously described. These factors can affect the way that communication signals are perceived. The individual differences and their effect on the interpretation of communication were also evident, as the results concerning the global judgments made by the two observers in Paper II were often different.

In Paper IV, barriers against psychosocial communication were explored from the oncologists’ perspective. The oncologists’ key attributes, such as their own needs, skills, values, beliefs, and emotions, are probably essential for the perception and ways of handling these barriers. The results from Paper IV also suggests that the more psychosocial oriented the oncologist is the fewer barriers are perceived. The environment and external factors, such as resources and organization of care also affect the frames in which the oncologists are able to act as professionals. These frames can sometimes be limiting, causing barriers against psychosocial communication in oncology care.

Implications for clinical practice

The results from this thesis are applicable to the clinical practice of oncology care. The results found can be used to further improve patient-physician communication and psychosocial care for patients with cancer.

Communication in oncology care has been researched during recent decades, and today there is much knowledge on how to improve it, both concerning how communication is delivered and in terms of what is being discussed. However, it seems that more research findings could be disseminated into clinical practice. In nursing research, one reason for this discrepancy between optimal care and reality has been suggested to be the lack of multifaceted interventions aiming at both organizational structures and working relationships, along with increased knowledge (177). Multi-level interventions have been suggested for improved cancer care delivery (178). Such initia-
tives are further supported by the multifaceted barriers against psychosocial communication found in Paper IV. Below are some suggestions made to inspire healthcare organizations towards better communication and better psychosocial care of patients with cancer.

Communication skills training

According to Paper IV, one-third (33%) of all Swedish oncologists perceive that they lack knowledge on how to communicate regarding psychosocial aspects with their patients. One way to reduce this problem is to support oncologists by offering supplementary communication skills training, and possibilities to get individual feedback of their own communication behaviors and/or to discuss communication difficulties and solutions with peers.

Communication skills can be improved by specific training programs (114, 116, 118, 136, 173, 179) and long-lasting effects have been shown (179, 180). Recommendations to guide the formulation of such training have also been developed (181). Communication skills training does not only include traditional courses; it can also include discussion groups, such as Balint Groups/Balint-like groups, where peer-to-peer exchange is essential. In such forums the possibility to discuss problems and solutions to problems with other professionals in the same situation could be valuable (182, 183).

It has been recommended that supplementary communication skills training should be offered to professionals on all levels in oncology care (181). In the postgraduate setting, such training has been recommended in the form of a mandatory basic course and other advanced courses on specific objectives such as discussing treatment options, end-of-life issues, or identifying and treating psychosocial distress (181). To be efficient, the training should focus on the rationale of why communication is essential, and include practical exercises and individual feedback on communication behavior (116, 181). The results from Paper IV show that those oncologists who had some supplementary education with psychosocial focus perceived fewer barriers against psychosocial communication and were more psychosocially oriented, which could indicate the value of communication skills training for clinically active oncologists. However, the results found in Paper IV could also be due to selection bias, as those participating in such training might be more psychosocially oriented and perceive fewer barriers from the start.

Guidelines and quality indicators

Paper IV, states that many of the Swedish oncologists perceive lack of guidelines and routines for handling patients’ psychosocial problems. This could indicate that the now-existing Swedish guidelines are not optimal or
not fully implemented in clinical practice. This might be an area in need of further development.

Modern guidelines have specified standards for assessment of patients’ psychosocial concerns and needs for support (37, 107). The assessment may involve a combination of self-report questionnaires and interview approaches, but is dependent on effective patient-physician communication. This is why supplementary education of all members of the oncology team could be introduced to ensure competent assessment of patients psychosocial healthcare needs (37).

Although guidelines are crucial to obtain safe and equal psychosocial care of patients with cancer, studies show that implementation of such guidelines is difficult (26, 184). Only 53% of the institutions in USA have implemented the NCCN guidelines, and routinely assess patient distress (184). Furthermore, studies keep showing a high prevalence of non-addressed psychosocial problems among cancer patients despite new guidelines (41, 87). Possible reasons for poor implementation of guidelines might include that the guidelines have been developed by non-clinicians and therefore are not realistic. Another explanation could be that different guidelines might be contradictory or that there are other possible organizational barriers to implementing the guidelines. The individual perspective of the oncologist may also affect if and to what extent guidelines are implemented.

Possible approaches to improving the implementation of guidelines are to develop them in close cooperation with clinicians and to re-enforce the guidelines with information and training. Furthermore, continual assessment could be made of the quality of psychosocial care in outpatient medical oncology settings, for instance by using quality indicators (185).

**Systematic use of PROMs in clinical practice**

In Paper IV, more than half of the respondents perceived that there was a lack of good methods for evaluating patients’ psychosocial health in clinical practice. Introducing PROMs in clinical practice could highlight patients’ concerns (186) and can improve the focus during the consultations on symptoms/problems that need attention and can allow for the physician to quickly determine if symptoms are worsening or improving over time. Using PROMs in clinical practice can also facilitate better more patient-centered communication by working as a reminder to discuss specific topics (187, 188). However, few PROMs are used in a systematic way in clinical oncology practice. The new technologies now available allow outpatients to electronically report PROMs via internet or cellphone and the results can be connected directly to the patients’ electronic journals, making it possible to
get safe, updated information on the patients’ status continually (187). Time constraints and varying relevance of questions included in the PROMs are examples of barriers against implementation of PROMs in clinical practice (188). There is a need to tailor the PROMs to the individual patient, based on cancer type, stage, treatment, and personal preferences. This can be accomplished by the addition of a prompt list in which the patient can indicate which issues they want to discuss (189), or by the use of computer-adaptive tests, by which the questions could be efficiently tailored to the issues relevant to the specific patient (188). Barriers against implementation of PROMs in clinical practice involve changing the behavior of individuals (both patients and physicians), but there are also organizational and financial challenges (174).

Implications for future research

The character of the Swedish outpatient oncology consultations shows that the physical aspect of the disease and treatment are in focus. However, though these issues often are discussed, misunderstandings concerning issues such as treatment aims or severe side effects were noted, which indicates that quantity and quality of communication is not equivalent. The medical discussions can be difficult for patients to comprehend due to reasons such as the medical terminology, and/or the emotional stress they might be under. In this thesis the quality of the medical information was not assessed further. It could be valuable to assess what information patients receive about treatment and how often patients misunderstand the medical information given. It would also be valuable to evaluate possible interventions for reducing such misunderstandings between patients and oncologists.

Until today, cancer care research has primarily focused on single-level intervention studies, primarily targeted at changing physician and/or patient behavior (190, 191). These include communication skills training (115-117), or implementation of HRQoL-instruments in clinical practice (132, 134). However, scientific advances are applied within an increasingly complex social, organizational, and environmental context, where multi-level intervention research could be used for understanding how to improve cancer care delivery (178). Consequently, interventions aiming at eliminating or reducing the barriers found in Paper IV could simultaneously be targeting different levels to reach significant effects on clinical practice. This thesis can hopefully contribute to future research based on the knowledge about identifying the most clinically important barriers against psychosocial communication. It would, for example, be interesting to design an intervention where some of these barriers are being met. A multilevel intervention could include communication skills training, introduction of an ePROM in clinical practice,
and optimization and further implementation of existing guidelines. However, multilevel interventions’ complexity also complicates the assessment of the effects of the different parts.

The barriers detected in Paper IV could be further studied in relation to how they affect clinical practice and how they each are handled by the physicians. Consultation time was frequently perceived as a barrier for psychosocial communication (Paper IV). It would thus be valuable to further explore the effect of time on consultation content and quality, and see if more consultation time automatically leads to more psychosocial issues being discussed. One study has shown that talking about psychosocial issues does not prolong the consultation, but actually can shorten the consultation length (192). It would also be interesting to evaluate whether, and if so, how much longer consultation time is needed, for the oncologists to feel comfortable with discussing both physical and psychosocial aspects during the consultations.

This thesis has partially focused on barriers against discussing psychosocial issues from the oncologists’ perspective. Research aiming to improve the patient-physician communication should also include the patient perspective, with regard to what affects whether or not patients initiate psychosocial topics, and possible interventions supporting patients’ ability to address these issues.

Paper III showed that patients and physicians to some extent had different views of what had been discussed during the consultations. Another study has shown that different perspectives (those of patient, physician, and observer) have different views on what had been discussed in relation to phase I clinical trial discussions (193). This is interesting to study further both for methodological reasons and for practice implications as different perspectives, especially between the patient and the physician, might explain problems in patient-physician communication. This may include misunderstandings and different views on medical decision making.

**Methodological limitations**

The generalizability of the results from this thesis to other settings must be made with some caution, because differences in healthcare systems and the roles of the oncologist may differ, which could affect the results. The results in Papers I, II, and III primarily apply to GI cancer. It is possible that studying patients with other cancer diagnoses could produce different results. However, the results could be applicable to other cancer diagnoses (and possibly to other diseases) with similar disease burden profiles with complex treatments, stigma, prognosis, and impact on QoL.
The sample size in Paper I-III was limited and mainly adjusted to fit another study’s purpose, being a historical control group. A larger study number would be required to increase statistical power and to be able to generalize the conclusions to a greater extent. There is a risk of selection bias as the oncologists participating could differ systematically from the total population of oncologists. Especially outliers could affect the results’ generalizability. However, data was collected from two different hospitals in Sweden, one university hospital and one emergency (general) hospital. The oncologists participating were limited in number, but were heterogenic with respect to gender, age, and work experience.

The methods evaluated in this thesis focus on verbal communication. However, communication is much more than the spoken words. Body language, mimicry, gestures, and eye contact are all ways of communication, which are also interpreted and can be acted upon. These important aspects of communication are missed when using audio recording as a means of collecting data.

There is a risk that the character of the consultations was affected by the fact that both patients and physicians knew that they were audio-recorded, presenting a possibility of observation bias. The oncologists might have been affected due to the social desirability of discussing more psychosocial issues than usual. Patients might have been affected by the recordings as well, being less willing to initiate sensitive discussions, including problems of a psychosocial character like emotional or sexual functioning. However, it is likely that the physicians became accustomed to being recorded. Audio-recordings are generally well accepted (194) and have proven not to significantly affect the consultations. The results show that psychosocial and QoL-aspects were not always discussed, suggesting that the oncologists were not significantly affected by the recordings. Another explanation could be that these issues might be even less frequently discussed when not audio-recorded.

Recall bias could have affected the responses to the content questionnaires in Paper III; however this risk was minimized as the questionnaires were completed directly after the consultations. Nonetheless, the fact that the patients filled out the questionnaires at the department could have influenced responses and possibly led to a social desirability effect, contributing to the high scores on the communication quality question (PQC-VAS). Again, high scores on the PQC-VAS could also been explained by the ceiling effect often associated with patient-satisfaction scales (133, 134, 195-200) or by other factors, like gratitude or the Hawthorne effect (196).
It is possible that the patients’ perspective concerning what had been discussed and the quality of the consultation could have been assessed by interviews after the consultations instead of self-report questionnaires. Interviews could have given additional and deeper information in relation to certain aspects. The rational for using self-report questionnaires were due to practical and logistical issues, since this was a historical control group. The social desirability using interviews might have been even higher as the research assistants were dressed in healthcare staff uniforms due to hospitals regulations.

Paper IV had a response rate of 64% which is high for a physician questionnaire (201), but still less than optimal. High response rates can reduce the risk of selection bias and thereby enhance the surveys’ usefulness. Non-respondents could be significantly different from the respondents, which could give an unrepresentative result. In Paper IV, no differences between respondent and non-respondents concerning gender distribution were seen. Representativeness in other aspects was not possible to asses.

Paper IV explores the number of barriers and the extent to which they are perceived as affecting clinical practice. However, no further hierarchy analyses could be made of how different barriers affecting clinical practice were perceived in comparison with each other. To compare the barriers against each other would be interesting to explore further, as one of the barriers could be of much greater importance than several of the others taken together.

In Paper IV many statistical comparisons were made, and even though Bonferroni correction was used as a post-hoc test in relation to the Stepwise ANOVA analysis, caution must be taken as there could be statistical significances generated by the large number of analyses.
Conclusions

The solution of a problem is another problem
Johann Wolfgang von Goethe (1749-1832)

This thesis shows that patient-physician consultations in GI-oncology care are focused on the physical aspects of disease and treatment in terms of how often these issues were discussed and in the amount of time spent on discussing them. Psychosocial issues, such as the disease’s effects on patients’ emotional or social functioning, are not always discussed during consultations, and the time spent on such discussions is limited. When psychosocial issues are discussed during the medical consultations, they are most often patient-initiated. Reasons for why psychosocial aspects are seldom discussed during the medical consultations can be the barriers concerning this kind of communication perceived by a large majority (93%) of the oncologists. The barriers against psychosocial communication identified are on both organizational levels (including guidelines, routines, and resources) and individual levels (including physicians’ knowledge and attitudes).

Furthermore, this thesis shows that there are methods that have good reliability and feasibility for evaluating the content of patient-physician communication, in large study samples in oncology care. The method (observation/self-report) and perspective (patient, physician, and observer) used when evaluating communication can affect the results. This needs to be considered when choosing evaluation methods in intervention studies.

Specific conclusions

Content and character of communication

- The character of the patient-physician communication in GI cancer care can be described in seven main areas. These are: Disease and treatment, Healthcare planning, Everyday living, Psychological wellbeing, Coping with disease, Expressions of concerns and feelings, and Other aspects of communication.
• According to the quantitative content analysis, the most commonly discussed topics were overall health, bowel symptoms, and pain. Topics including emotional, social, cognitive, and sexual functioning were discussed less frequently during the consultations.

• The proportion of time spent on discussing physical and medical issues dominate (78%, range 59-93%) during the consultations, while psychosocial issues were discussed less, and sometimes not at all (16%, range 0-41%).

• The observations showed that the physician most often introduced overall health and pain discussions. For other topics the initiative was either equally distributed or patient-initiated. When emotional functioning was discussed, it was most often (71%) initiated by the patients themselves.

• According to the patients, emotional functioning was discussed in 63% of the consultations. Physicians perceived that emotional functioning was discussed in 80% of the consultations.

• Patients rated the overall quality of the communication highest, with (mean value 92), followed by the physicians (mean value 78). The observer rated the communication quality the lowest (mean value 71). Patients’ ratings of the communication quality differed significantly (p ≤ 0.05) from both the physicians and the observers.

Barriers and psychosocial orientation

• Virtually all oncologists (93%) experienced one or more barriers in communicating about psychosocial issues with their patients, and most oncologists (79%) perceived that one or more barriers have some or a large impact on their clinical practice. The barriers most commonly affecting clinical practice were: “insufficient consultation time”, “lack of resources for taking care of the psychosocial problems discovered”, and “lack of good methods in clinical practice to evaluate patients’ psychosocial health”.

• Oncologists who perceived the most barriers were also those who were less psychosocially oriented (r_s=0.490, p< 0.0001).
Methods for evaluation of communication

- Sensitive instruments to measure psychosocial aspects are needed to evaluate effects of interventions that target these aspects of communication. In detailed IAS, communication of psychosocial character may be captured too briefly and too generally. Further development is suggested to allow for IAS to discriminate between different psychosocial areas such as emotional, social, and cognitive functioning.

- The Swedish version of VCAS showed good to excellent inter-rater agreement, and MIPS global scale showed fair to good inter-rater agreement.

- The method of using VCAS and MIPS global scale combined covered most of the consultation content detected by Paper I, i.e. it had good content validity. The areas not measured by these instruments were pauses, jokes, and detailed quantification of speech activities, such as number of open-ended questions etc. The feasibility of using VCAS and MIPS global scale makes it suitable to use in large studies where many consultations (>100) are analyzed, and where the research focus is mainly on topics discussed and who initiated them.

- Differences were shown in self-reported communication content and perceptions of the quality of the communication from the perspective of patients, physicians and independent observers. This has to be considered when choosing methods or evaluating research results using different methods/perspectives.
Key messages

For researchers: This thesis support the need to continue to evaluate and promote patient-centered communication in the oncology setting, with focus on improving the discussions concerning the psychosocial areas. It is important to apply promising ways of achieving more patient-centered communication, e.g., by the implementation of PROMs and offering supplementary communication education for healthcare personnel. However, simultaneously researchers need to be aware of barriers against psychosocial communication to improve the results with regard to psychosocial care interventions in clinical practice.

For oncologists: To achieve patient-centered care, a complete, holistic perspective of the patient is necessary. This includes addressing both physical and psychosocial aspects during consultations, for making the best possible medical evaluations and treatment decisions. If the patient does not spontaneously initiate psychosocial problems, this does not per se mean that they do not have any. Healthcare professionals should therefore see to that all possible disease-related problems are detected during the consultation, at the same time as considering patient integrity. Sometimes patients and oncologists perceive the content of a consultation differently. Checking patients understanding is therefore essential to reduce possible misunderstandings. Barriers against psychosocial communication during consultations are commonly perceived by oncologists. These barriers need to be handled to improve the care of patients with cancer and reduce the stress burden on oncologists.

For patients: To achieve the best possible care, all aspects of life that somehow is affected by the cancer, e.g. symptoms, side effects and psychosocial problems, are of importance to the treating oncologist. These aspects are important as the knowledge about them can help the oncologist to adjust the treatment and care according to patients individual needs. The information about psychosocial issues can occasionally lead to referrals to other healthcare professionals better equipped handling these issues.

For society: If the society aims to provide patient-centered oncology care, the barriers for psychosocial communication must be acknowledged and handled. Facilitators, such as enough consultation time, possibility for healthcare personal to attend supplementary education with focus on communication, and increased evaluation patients psychosocial health in clinical practice should be ensured and implemented.
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“Thank the flame for its light, but do not forget the lamp holder standing in the shade with constancy of patience”
(Rabindranath Tagore 1861-1941)

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Kommunikationen mellan vårdgivare och patient är av central betydelse för att uppnå en optimal vård och behandling anpassad efter patientens behov och önskemål. En tillfredsställande kommunikation kan bidra till att rätt diagnos kan ställas samt att rätt behandling kan ges och följas upp. Inom cancervården är kommunikation av särskilt stor vikt eftersom det rör en livshotande sjukdom, som ofta innebär en hög emotionell och psykisk påfrestning för patienten. Detta i kombination med komplicerade behandlingsregimer, hög biverkningsrisk och osäkert utfall av behandlingen medför ett stort behov av information, stöd och dialog. Behovet varierar dock i hög grad mellan individer men varierar också genom sjukdomsprocessens olika faser.

Tidigare forskning har visat att kommunikationen mellan patient och läkare inom cancervården haft brister, vilket t ex kan leda till att patienten missförstår information kring behandlingen, eller att viktiga problem och symptom inte diskuteras. Mycket forskning har koncentrerats till att förbättra kommunikationen. Exempel på sådana interventioner är införandet av PROMs (patientrapporterade data) som t ex livskvalitetsinstrument i klinisk onkologisk rutinvård. Ett annat exempel är utbildningsinsatser i syfte att förbättra läkares kommunikationsförmåga. För att kunna utvärdera kommunikationen vid läkarbesök behövs valida och tillförlitliga metoder.

Den vetenskapliga litteraturen samt resultat från de första delarbetena i avhandlingen pekar på att psykosociala aspekter av cancersjukdomen inte alltid diskuteras. I avhandlingen återfinns en tidsanalys som visar att fokus vid läkarbesöken var på de medicinska/fysiska aspekterna av sjukdomen och behandlingen, medan psykosociala områden inte alltid diskuteras. Vidare är dessa ämnen, när de väl diskuteras, oftast initierade av patienterna. Därför undersöktes onkologers syn på att samtala om psykosociala ämnen och vilka barriärer de upplever kring detta. Resultatet visar att en majoritet (93%) av Sveriges onkologer upplever en eller flera barriärer när det gäller att samtala om psykosociala frågor med patienter. Vidare anger många onkologer att dessa barriärer påverkar deras kliniska agerande.

Avhandlingen omfattar även en studie kring reliabilitet och användarvänlighet av en kombination av två olika kommunikationsanalyseinstrument som använts och utvecklats för att mäta kommunikation inom onkologisk vård. Det ena kommunikationsanalyseinstrumentet (VCAS) är ett innehållsanalysinstrument som mäter vilka samtalsområden som uppkommer, om ämnet diskuteras eller nämns samt vem som initierar samtalsämnet. Det andra instrumentet (MIPS global scale) utgörs av globala sub-skalar på vilka en obeservatör gör övergripande bedömningar av kommunikationen i olika avseenden, t ex läkarbesöks grad av patientcentrering, psykosocialt fokus och läkarens grad av lyhördhet. Avhandlingen omfattar även en jämförelse av olika metoder (observation, självrapporiterade utfall) och olika perspektivs (patient, läkare, observatör) samstämmighet gällande huruvida läkarbesöket innehåll diskussion kring patientens emotionella funktion, samt kvaliteten på kommunikationen.

Slutsatsen av denna avhandling är att de onkologiska läkarbesöken främst behandlar de fysiska aspekterna av cancersjukdomen och att de psykosociala aspekterna av sjukdomen inte alltid diskuteras. Detta kan leda till att problem av psykosocial karaktär riskerar att förbli oupptäckta, vilket i sin tur kan leda till onödigt lidande för patienter med cancer. Avhandlingen visar också att onkologer upplever en rad olika barriärer vid kommunikation kring psykosociala frågor med patienter, varav många påverkar deras kliniska arbete. Åtgärder behöver vidtas för att minska eller eliminera dessa barriärer för att förbättra vård och behandling av patienter med cancer samt för att förbättra onkologernas arbetssituation.

Avhandlingen visar också att olika typer av metoder för att mäta kommunikation ger olika resultat. Att använda olika typer av metoder och metoder som utgår från olika perspektiv (patient, läkare, observatör) kan vara värdefullt i forskningssammanhang då de olika metoderna kan komplettera varandra och ge en djupare förståelse för kommunikationens innehåll och kvalitet.
Vidare visar avhandlingen att det finns kommunikationsanalysinstrument som mäter kommunikationens innehåll (innehållsanalysinstrument) som har god användarvänlighet och god reliabilitet. Kommunikationsanalysinstrument som mäter kommunikationen på en global skala uppvisade sämre reliabilitet och behöver utvecklas vidare avseende bättre användar- och träningsmanual. De kommunikationsanalysinstrument som mäter både innehåll och beteende (interaktionsanalysinstrumenten) kan utvecklas genom att i högre grad skilja mellan olika typer av psykosociala aspekter, t.ex. social funktion och emotionell funktion.
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A doctoral dissertation from the Faculty of Pharmacy, Uppsala University, is usually a summary of a number of papers. A few copies of the complete dissertation are kept at major Swedish research libraries, while the summary alone is distributed internationally through the series Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Pharmacy.