Health-related Internet use and screening for emotional distress in people with cancer

SUSANNE MATTSSON
The overall aim of this thesis was to investigate the preferences and incentives for using Internet-delivered support among people with cancer and to develop and test a generic questionnaire measuring health-related Internet use, the Health Online Support Questionnaire (HOSQ). Another aim was to examine the psychometric properties of the online-administered Hospital Anxiety and Depression Scale (HADS) and Visual Analogue Scale (VAS) regarding anxiety and depression in psychosocial screening among people with cancer, in comparisons with the longer instruments Montgomery Åsberg Depression Rating Scale – Self-report (MADRS-S) and the State Trait Anxiety Inventory – State (STAI-S).

Study I was a correlational and descriptive study on the development and psychometric properties of the HOSQ. Study II was a cross-sectional and descriptive study on health related Internet use in patients with cancer. Study III was a cross-sectional and descriptive study examining preferences for psychological treatments. Study IV was a psychometric comparison study of two short instruments and two longer instruments measuring anxiety and depression.

Findings from study I showed that the HOSQ might be a reliable and valid instrument for measuring the use of online support for people with health problems. Results ought to be replicated though in larger and other groups to confirm the results for different diagnoses. Findings from study II confirmed results from other studies showing that people with cancer turn to the Internet for informational support that enables them to influence their care and to stay in touch with friends and relatives. Demographical differences regarding the uptake of Internet-based support remains, which indicates a need for research on how to bridge this digital gap. In study III, we found that a large majority preferred psychological treatment face to face whereas Internet-based interventions were reported as the preferred choice by a minority. Findings from the content analysis suggest that Internet-based interventions have specific advantages that may facilitate help-seeking among some individuals and some disadvantages that may be perceived as barriers. Initiatives to increase treatment acceptability may benefit from addressing the advantages and disadvantages reported in this study. In study IV we found that the use of the short and ultrashort tools HADS and VAS identified anxiety and depression in patients with cancer with high accuracy in comparisons with the longer instruments.

In conclusion, online screening with the HADS and VAS may be a suitable initial method to identify anxiety and depression in patients with cancer. There is still a large proportion of patients who lack the interest or eHealth literacy to use health-related support on the Internet. By learning more about the barriers, use and perception of eHealth and Internet-based interventions, adequate support may be offered.

Keywords: Social support, Internet, Cancer, eHealth, Questionnaire, Oncology, Support, Patient preference, Screening, Depression, Anxiety
To Leon and Jonathan
List of Papers

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


Reprints were made with the permission of the respective publishers.
Abbreviations

AUC  Area Under the Curve
BI   Behaviour Intention
CFA  Confirmatory Factor Analysis
CBT  Cognitive Behavioural Therapy
EE   Effort Expectancy
EFA  Exploratory Factor Analysis
FCO  Facilitating Conditions
HOSQ Health Online Support Questionnaire
HRQoL Health-Related Quality of Life
HADS Hospital Anxiety and Depression Scale
ICBT Internet-administered Cognitive Behavioural Therapy
IT   Information Technology
MADRS-S Montgomery Åsberg Depression Rating Scale-Selfreport
PAF  Principal Axis Factoring
PE   Performance Expectancy
RCT  Randomised Controlled Trial
ROC-curve Receiver Operating Characteristic-curve
VAS  Visual Analogue Scale
SI   Social Influence
STAI-S State Trait Anxiety Inventory-State
UTAUT Unified Theory of Acceptance and Use of Technology
ASCO American Society of Clinical Oncology
SALAR Swedish Association of Local Authorities and Regions
GP   General Practitioner
SKL  Sveriges kommuner och landsting
Introduction

Being diagnosed with cancer may entail many challenging experiences. It often questions the belief that life is predictable and controllable and may turn the commonly held world upside down. Existential matters related to the awareness of one’s own mortality may intrude in a brutal way. Changes in lifestyle and appearance and decreased functional abilities can be difficult to accept and adjust to as well as altered future plans. Disease and treatment side effects e.g. fatigue, pain or other symptoms may have a negative impact on quality of life and may decrease the ability to maintain the same level of social life with friends and family. When the treatments are over and the disease is in remission the fear of relapse may lead to anxious monitoring of every physical expression that could be a sign. The group of cancer survivors is growing and the survival rate has increased rapidly over the past decades. This is a vulnerable group due to potential sequelae of the disease and treatments which has a higher risk for psychosocial comorbidities and psychosocial problems throughout their lifetime [1].

Over the past decades there has been a shift in the healthcare system, where patients with cancer to a large extent are treated in outpatient clinics and are supposed to care for themselves in many ways in the time period between and after treatments. This has many advantages for patients who can stay in their home environments, avoiding being exposed to other diseases and the sometimes stressful environment at the clinic. On the other hand, the monitoring of negative consequences of the disease or treatment that used to be taken care of by the staff involved in the bedside care is now, to a larger extent, transferred to the patient. The natural room for interaction with staff and fellow patients takes place when the patient goes to the hospital for treatments or other appointments. The rest of the time the patient has to decide whether to call the hospital or not or turn to any other source of support if they encounter any problem or a question arises. This can be an aggravating circumstance for participation in care if the patient experiences a lack of information and other support. A deeper understanding of the difficulties people face following a cancer diagnosis and treatment and how the healthcare system should respond to these problems is an important factor in cancer care. The Internet may be a valuable source of information and other types of support. It is therefore important to investigate how health-related Internet use is perceived among patients with cancer in order to develop and provide adequate support.
Cancer incidence and treatment-related factors

Cancer is one of our times’ major diseases and it has been estimated that at least every third person in Sweden will be diagnosed with cancer during their lifetime. Cancer is a generic term for approximately 200 diseases and in Sweden breast cancer is the most common cancer among women and prostate cancer the most common cancer among men. Skin cancer is the second most common among both women and men and colorectal cancer is the third most common form of cancer. During the past two decades, the incidence has increased by an average of 2.4% per year for men and 2% for women and in 2015, approximately 61,000 new cases were reported to the Swedish Cancer Registry. The increase is explained by an ageing population, lifestyle factors, screening and improved diagnostic methods [2, 3]. There are different treatments and the most common are surgery, radiation and chemotherapy. The treatments are getting more sophisticated because of continuous research and development and many of them generate less side effects than previous treatments. On the other hand, the treatment periods are usually longer than before. The choice of treatments depends on the diagnosis and stage of the disease. Some malignancies can never be cured by surgery, i.e. leukaemia, while other malignancies have to be removed by surgery. Patients may undergo just one form of treatment, but it is common for multiple treatments to be used in combination. Research has shown that the patients who are treated with chemotherapy report higher levels of symptoms and psychological distress compared to the ones who are not [4]. Advanced disease, lower age and female gender are also associated with higher levels of distress compared to older individuals, males and early stages of the disease [5, 6].

Psychological distress and social support in patients with cancer

The National Comprehensive Cancer Network (NCCN) defines distress as:

“A multifactorial, unpleasant emotional experience of a psychological (cognitive, behavioral, emotional) social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis” p.192[7].

People facing a severe disease often report psychological distress secondarily to their disease [8], but a majority of patients with cancer seem to have a good
ability to handle the strain [9]. The reported prevalence of anxiety and depression varies widely across studies but according to one study in a consecutively screened sample of more than 10,000 patients with cancer, approximately 18% reported clinical symptoms of anxiety and 13% clinical symptoms of depression [6]. Another systematic review and meta-analysis in a pooled sample of cancer survivors found that the prevalence of anxiety and depression was 17.9% and 11.6% respectively as compared to healthy controls where the prevalence of anxiety was 13.9% and depression 10.2% [10]. These prevalences can be compared with data in a Swedish population study where 1.2% of the women and 0.6% of the men reported that they had been diagnosed with generalised anxiety and 6.6% of women and 3.0% of the men that they had been diagnosed with depression [11]. Depression and anxiety in patients with cancer are associated with poor treatment adherence, which may lead to poor prognosis. It is also associated with lower health-related quality of life (HRQoL) and disease-related morbidity [12-18]. The provision of adequate support at an early stage might prevent the development of sustaining problems. It is therefore important to find efficient ways to identify the patients with anxiety and depression symptoms.

The perception of having sufficient social support is associated with a better HRQoL, less stress symptoms and better health [19-21]. It has also been found that it may relieve depression and anxiety and improve quality of life in people with severe diseases such as cancer [22, 23]. The sociologist James House developed a theory that states that social support can be categorised into four broad classes of supportive behaviours or acts, namely, informational, instrumental, emotional and appraisal [24]. Informational support can be described as advice or counselling that is helpful for coping with personal and environmental problems. Instrumental support is described as practical or economic help. Emotional support encompasses empathy, love, caring and trust and Appraisal takes the form of information that individuals use in appraising themselves such as feedback on performance or information that enables social comparison. The overall label “social support” could be questioned in the context of Internet-administered support but the different categories of support described by House could most likely also be found on the Internet [25-28]. The psychosocial structure around the patient is a factor that should be considered by healthcare since it has been found as an important factor for quality of life. It is important that the healthcare system manages to find the patients in need of additional support and provide it according to their needs. This requires knowledge on whether the patients perceive that they have the support that they need.
The need of psychological support for patients with cancer

In 1980, researchers and policymakers in healthcare started to pay increased attention to the psychological consequences of cancer and rehabilitation programmes that were offered to patients after treatment. In the early 90s, research was conducted showing that patients undergoing these rehabilitation programmes had better outcomes than the control group [29, 30]. A growing interest was seen in Sweden and worldwide in interventions to alleviate distress and sustain or increase health-related quality of life in patients. Swedish research showed positive outcomes on overall wellbeing in patients receiving supportive interventions encompassing responsible nurses monitoring physical, psychological, social, existential and financial problems and referral according to their needs [31]. A bit later on, a large Swedish randomised controlled trial (RCT) showed that there were no differences in outcome between the patients receiving interventions and the ones receiving standard care. These results challenged the notion that a majority of patients needed psychosocial support. It was thus concluded that a majority of patients with cancer had their needs met in standard care and that the patients in need of additional support needed to be identified. Screening was then recommended to target this group [32].

A lot of research shows that psychological interventions are efficient in reducing distress in patients with cancer but there are ambiguous results. In one review it was found that there are strong indications of the efficiency of psychological interventions [33]. Another review suggests the opposite and claims that the more robust the study is, the more likely it is that psychological interventions are found insufficient [34]. A plausible explanation could be that psychosocial interventions are mainly beneficial for people who report psychological distress, which is why screening is recommended to target these individuals [35]. There are national guidelines in several countries today that recommend routine screening for emotional distress in patients with cancer [17, 36-38]. The American Society of Clinical Oncology (ASCO) has developed guidelines to identify and treat depression and anxiety since these increase the risk for potential disease-related morbidity, poor quality of life and mortality [39]. In Sweden, according to the national programme for cancer rehabilitation, 2017, the government and the Swedish Association of Local Authorities and Regions (SALAR) have stated that patients should be assessed for anxiety and depression initially and repeatedly during the disease trajectory and referred to adequate support if it is needed. Routine screening is problematised, though, since symptoms of anxiety and depression do not necessarily mean that a person require additional support from the healthcare system [40]. Thus, the practice of routine screening is partly questioned and controversial [41] since the findings show ambiguous results [42, 43]. However, a recent review concluded that screening enhances
psychosocial referrals, benefits communication and improves patient wellbeing when effectively implemented [44]. Moreover, it has been reported that healthcare staff in cancer settings usually fail to detect patients with anxiety and depression due to barriers such as lack of time or skills on how to diagnose these symptoms [45]. In order to find the people at risk, screening instruments are used [46]. There are several international screening instruments that can be divided into long, short and ultra-short instruments. The short instruments usually have a higher clinical acceptance since they are less time-consuming to answer and analyse. They rarely have a high specificity though, and for some the sensitivity has been questioned as well. The specificity is the ability to rule out the ones without symptoms and the sensitivity is the ability to find the ones with symptoms. The longer instruments usually have a higher specificity and provide more reliable estimates but may be perceived as challenging and time-consuming to answer and analyse. By initially screening all patients with a short instrument followed by an assessment with a longer instrument for those with potential problems, the individuals in need of additional support could be identified with limited effort [47]. In a study at a large cancer centre, routine online distress screening was found to be both feasible and potentially helpful in reducing future distress levels [48]. These kinds of studies need to be replicated in future research due to the novelty of online screening. In order to identify the patients with emotional distress we need to find efficient methods to implement routine screening. That way we can offer support to the ones who need it.

The participating patient

During the past decades, the care of patients has shifted towards a culture where patients are encouraged to participate and take a bigger responsibility for their own care. In 2015, an updated legislation was launched in Sweden in order to strengthen and clarify the patient role and to promote patient integrity, autonomy and participation [49]. The development towards a more empowered and self-determined patient, who is to be considered as informed and partaking in the care, is thus continuing. Research have shown that a majority of patients with cancer prefer shared roles in decision-making about their cancer [50]. Other findings on information technology (IT) and patient empowerment in patients with cancer demonstrate that IT services can contribute to empowerment by providing knowledge [51]. Thus, the healthcare system needs to make sure that the sources of information and other support are customised so that they reach out to all patients and enable adequate levels of self-efficacy and participation in care. The provision of Internet-based information and other forms of support may help patients to stay informed and participate in the care decisions.
In 2016, a new eHealth vision for healthcare and social services was established by the government and the SALAR (Sveriges kommuner och landsting, SKL). It was called Vision eHealth 2025 and assumes that by 2025 Sweden will be world-leading in using digitalisation to promote equity in healthcare and social services. The use of the Internet for health-related support has increased [52] and people turn there for health-related support of various kinds [53]. Eysenbach has defined eHealth as:

"eHealth is an emerging field in the intersection of medical informatics, public health, and business referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking to improve health care locally, regionally, and worldwide by using information and communication technology." Table 4 [54].

The use of computers, mobile phones and tablets for health-related support, referred to as eHealth, is a relatively new modality to promote well-being and self-care in the healthcare system, and is increasing in Sweden as well as in other countries. Recent research in a Swedish setting found that patients with cancer going through treatment found eHealth modalities a facilitating factor for mutual participation in care [55].

Sweden is one of the countries in the world with the highest Internet access. Approximately 93% of Swedish citizens have Internet access at home [56]. The elderly, 65 and older, is the age group who uses the Internet the least but the usage is steadily increasing [57]. This may be the most healthcare-consuming group who therefore would benefit the most from utilising eHealth systems, but for various reasons many of them do not. The Internet or computer access does not seem to be the primary impeding factor to Internet resistance but rather factors related to the willingness to use these IT services [26, 57]. There is a need to thoroughly investigate the incentives for the use of eHealth and preferences regarding psychological interventions in order to provide adequate support to people with health problems and severe disease.

Health-related support on the Internet – eHealth

Research has shown that people with chronic disease can benefit from using the Internet for health purposes [58-60] and that patients with cancer find the ease of communication, up-to-date information and peer support to be incentives for using the Internet [28]. Nevertheless, face-to-face health-related support involves communication with another human being, which by some can
be perceived as beneficial compared to the relatively limited communication that is offered in online support [61]. Factors associated with an increased use of the Internet for health purposes are youth, female gender, higher education, white-collar work, visits to the general practitioner (GP) during the past year and long-term illness or disabilities [62, 63]. Cancer is frequently searched for [64] and the Internet offers a range of health-related websites of varying quality regarding scientific basis for the provided information. Among patients with cancer, the use of the Internet as a source of health-related support has increased and is by many considered a significant source [65, 66]. The search for information is the most common activity, but they also visit online peer support networks, blogs and social networks [58, 67], which has been found to be a valuable source of social support [27].

However, the use of eHealth is influenced by sociodemographic characteristics, which needs to be further addressed [53]. Research has also identified Internet efficacy as a facilitating factor predicting the use of eHealth [68] and as such, knowledge on how to increase Internet efficacy among patients is required to increase the reach. Evidence regarding a patient’s current use and appreciation of the Internet as a tool for health-related support is important in order to develop customised support and enhance health self-efficacy and health care participation.

**Measures on the use of eHealth for support**

Since the development and use of eHealth is increasing, there is a need understand how the concept of social support can be incorporated in eHealth services. There is also a need to understand how these services are perceived, by whom they are accepted and not accepted, and the perceived barriers. There are many instruments on social support in an offline context but a lack of them in an online context. They usually fall into the categories of structural measures or functional measures. Structural measures take account of the network size, frequency or density, while functional measures take account of the quality of the structure, the emotional, appraisal, informational and instrumental aspects. The evaluation of the validity and reliability of these questionnaires is problematic though, because of the lack of psychometrical testing [69]. It is therefore important to develop psychometrically tested questionnaires that capture the aspects of online support. The knowledge about incentives and preferences of use of eHealth in different contexts and groups is important since the Internet has become such a significant source of health-related support [26, 62, 70-72]. A review from 2017 of measures on eHealth concludes that there is a lack of available psychometrically sound measures to evaluate eHealth technologies from patients and others’ perspectives [73]. The researchers also problematise that rapid development and changes in technol-
ogy challenge the development of up-to-date measures [73]. It is therefore important to develop psychometrically tested questionnaires to evaluate the use of eHealth.

Attitudes towards Internet-based psychological interventions

The development of and access to Internet-based psychological interventions enable a timesaving and efficient way to reach out to a large group of individuals in need of psychological support [74]. However, the support will fail to reach out if it is not perceived as efficient and acceptable among intended users. For persons faced with health problems and impairing health conditions, these kind of interventions may be efficient in providing support and alleviating psychological distress [75-78]. Despite this, and the fact that flexibility is enabled in time and place regarding the service use, implementation of these interventions in routine care has proven to be challenging [79, 80]. Internet-delivered interventions usually have problems with high dropout rates [81] and it is thereby important to investigate the diverse needs and expectations in order to retain people. The need for support varies and, as mentioned earlier, the level of distress in people diagnosed with cancer depends on disease- and treatment-related variables as well as demographical variables [6]. It is important to investigate the key determinants for the acceptance of these interventions in order to maintain adherence and increase overall outcome [82, 83]. It has been found that adherence increases if the individual can chose the treatment form instead of being allocated to a treatment without being able to influence the choice [83]. There are many sorts of interventions that comprise different sorts of support. Some of them are intended as sole treatment modules and others as complementary modules to other sorts of treatments [84]. Studies show that incentives for providing Internet-administered support are increased convenience for users, reduction of health service costs, overcoming isolation of users, stigma reduction and increased user and health provider control of the intervention [85]. Since Internet-delivered support usually consists of text-based material, it saves therapists time and may increase treatment fidelity [86]. On the other hand, there is a concern regarding a relationship with a virtual therapist, communicating emotional matters via a computer, confidentiality, trustworthiness of the system and privacy issues [87]. There are also perceived advantages about a sense of anonymity, which may enable some users to be more open about their situation [88]. It is important to investigate the perception of these interventions among patients with health alterations and severe diseases such as cancer before initiatives are implemented by policymakers.
Research regarding treatment acceptability among individuals without past or current use of Internet-administered psychological treatment has shown that the vast majority preferred treatment face to face [89]. Symptom severity was related to a lower interest in Internet-based interventions while time constraint was related to a higher interest [89]. Other research regarding perceived acceptability of Internet-based interventions in the general population, mostly consisting of university students using the Internet daily, showed that face-to-face interventions were preferred over Internet-administered treatment [61]. No significant differences regarding factors such as computer literacy, gender or previous or current mental health status were found [61]. The research on the acceptability of Internet-based interventions among individuals with and without past or current experience of these should be interpreted with caution, though, since they often employ online samples or patients already taking part in treatment programmes [90, 91]. It is therefore important to investigate the attitudes towards Internet-based interventions among people offline in order to find out more about the incentives for not using Internet-based support.

Theoretical framework

The Unified Theory of Acceptance and Use of Technology (UTAUT) [92] was developed by Venkatesh, Morris, Davis and Davis in 2003 and is an existing model or theoretical framework for analysing technology acceptance. The framework is designed to depict the intention to use technology and is an extension of the Technology Acceptance Model, TAM, which has been widely applied to examine the use of technology in different contexts [93]. The UTAUT is a model that can be used to analyse and explain the underlying factors for use of IT, which was investigated in Studies I-III. It could also be used to analyse the results regarding effort expectancy in Study IV.

The UTAUT is based on the comparison of eight different theories regarding determinants for acceptance and is an integrated synthesis of these theories. The ones included are the Theory of Reasoned Action (TRA) (Fishbein and Ajzen 1975), Diffusion of Innovation Theory (DOI) (Rogers 1995), Technology Acceptance Model (TAM) (Davis’s1989), the Motivational Model (MM) (Davis et al. 1992), Theory of planned behaviour (TPB) (Ajzen, 1991), the Combined Theory of Planned Behaviour/Technology Acceptance Model (C-TPB-TAM) (Taylor and Todd 1995), The Model of Personal Computer Utilization (MPCU) (Thompson et al.1991) and the Social Cognitive Theory (SCT) (Compeau & Higgins, 1995) [92]. The UTAUT is one of the most recent and empirically tested theories that examines the variables that can influence individuals to adopt and use technological support in various settings [94].
According to the UTAUT, there are four independent constructs or main aspects that influence either behavioural intention (BI) or usage behaviour (USE) to IT use. This model can be applied to the analysis of the results in the four studies in this thesis, which is described below.

I. Performance expectancy (PE)

This construct can be explained as the degree to which an individual believes that the use of the system will be helpful. In Study II, the participants were asked to rate how valuable they found different eHealth tools and in Study III, the participants were asked about perceived advantages and disadvantages of Internet-based psychological interventions and their preferences, which can be referred to as PE.

II. Effort expectancy (EE)

This construct can be explained as the degree of ease associated with the use of the system. In Studies I and II, the participants answered questions about Internet use for the purpose of searching for information or also sharing information. This can be analysed from an EE perspective in the sense that sharing may be more demanding than reading only. In Study III, the participants described advantages and disadvantages of psychological interventions which included EE and in Study IV, efficiency in ultra-short and short online-administered tools was investigated in order to find screening methods that are less demanding to answer and analyse than other existing screening methods, which is also related to EE.

III. Social influence (SI)

This construct could be explained as the degree to which an individual perceives that important others believe he or she should use the system. In Study II we examined the use and perceived value of using the Internet for informational and interactive support and in Study III we examined the preferences regarding Internet based versus face-to-face psychological support, which can be referred to as SI.
IV. Facilitating conditions (FCO)

This construct could be explained as the degree to which a person believes that an organisational and technical infrastructure exists to support use of the new system.

The UTAUT also takes moderating variables into account. These are age, gender, experience and voluntariness of use. These variables are hypothesised to moderate the influence of the four above-mentioned constructs on behavioural intention and use behaviour. In Studies I-III, age and gender related to different types of Internet use and preferences was examined.

Behavioural intention is referred to as the willingness of respondents to use the system. Usage behaviour constructs are often operationalised by self-reports by participants of their degree of current system use, such as how often they have logged in to a system over a period of time and how much time they have spent on the system. In Studies I, II and III, this was investigated through the use of the Health Online Support Questionnaire (HOSQ) and project-specific questions.

Figure 1. The UTAUT original model by Venkatesh (2003). An illustration on the four constructs influencing behavioural intention and usage behaviour and moderating variables. Copyright © 2004, Regents of the University of Minnesota. Used with permission.
The strongest correlation in the UTAUT model is the one between performance expectancy and behaviour intention. This was found in a recent meta-analysis examining the model in various settings [94]. The same meta-analysis found a large effect size for the relationship between facilitating conditions and behaviour intention and a medium effect size for the relationship between effort expectancy and behaviour intention, social influence and behaviour intention, behaviour intention and USE, and facilitating conditions and USE. The model is considered to be a good theory for identifying the determinants of intention to use information systems and information technology. A vast amount of research shows that the evaluation of how beneficial a system is to use and the effort and social influences that come with using it are the strongest predicting factors for willingness to use new information systems and technologies [94].
Rationale for the thesis

There is an impending shortage of healthcare resources due to a growing ageing population where the incidences of many chronic diseases and cancer are increasing. Finding efficient ways to meet the individual healthcare requirements of our citizens is crucial in order to achieve patient centred care. eHealth could be one of the solutions given that adequate information on the benefits, interventions with practical support, and education on how to use the systems are given to those who feel insecure or uncomfortable using it.

To be able to intervene and customise the support, knowledge about the preferences of Internet-administered support in different groups is required. Another important factor is knowledge about potential moderating factors such as age, gender and other variables and the different needs according to the moderating factors. There is also a need to understand the nature of the barriers for uptake of various forms of online support and interventions in order to help patients master these or to offer other types of support. Moreover, the healthcare has to find efficient ways to find the patients who suffer from anxiety and depression symptoms and may be in need of additional support.

The ambition of the present thesis was to develop and psychometrically test a generic questionnaire measuring the use of eHealth in people with health problems and severe disease such as cancer. Moreover, to study the use of eHealth and preferences regarding psychological support and to psychometrically test screening instruments measuring anxiety and depression in order to identify clinical levels of these symptoms in patients with cancer.

Evidence on the preferences and use of eHealth and psychological support as well as time-efficient and psychometrically sound methods to identify patients with distress are prerequisites for the healthcare system, researchers and policymakers to be able to intervene accordingly.
Overall and specific aims

The overall aim of this thesis was to develop and test a generic questionnaire measuring health-related Internet use and to investigate the preferences and incentives for using Internet-delivered support among people with cancer. Another aim was to examine the psychometric properties of the online-administered Hospital Anxiety and Depression Scale (HADS) and Visual Analogue Scale (VAS) regarding anxiety and depression in psychosocial screening in people with cancer, in comparisons with longer instruments.

Study I
The aim was to create a generic questionnaire regarding health-related Internet use that could be applied to various groups with health problems and sickness. An additional aim was to test the questionnaire in a cancer population to assess its adequacy in the context of severe illness.

Study II
The aim was to investigate health-related Internet use and the perceived value of this among people with cancer. A further aim was to explore the incentives for the use of the Internet and the associations with medical and demographic variables.

Study III
The aim was to evaluate the preference for Internet-based psychological interventions as compared to treatment delivered face to face among individuals without past or current use of psychological treatment delivered online. A further aim was to investigate predictors of treatment preference and to complement the quantitative analyses with qualitative data about the perceived advantages and disadvantages of Internet-based interventions.
Study IV

The aim was to investigate whether the short, HADS, and ultra-short, VAS, Internet-administered instruments provide a reliable basis for assessing anxiety and depression symptoms in patients with cancer, in comparison with the two longer instruments Montgomery Åsberg Depression Rating Scale – Self-report (MADRS-S) and State Trait Anxiety Inventory – State (STAI-S).
## Method

### Design

<table>
<thead>
<tr>
<th>Study design</th>
<th>Data collection</th>
<th>Study sample</th>
<th>Analyses</th>
</tr>
</thead>
<tbody>
<tr>
<td>I. Psychometric, quantitative, correlational and descriptive</td>
<td>Questionnaire</td>
<td>243 nonclinical 282 patients with cancer</td>
<td>Exploratory factor analysis Confirmatory factor analysis Logistic regressions Chi² Mann-Whitney U</td>
</tr>
<tr>
<td>II. Quantitative, cross-sectional and descriptive</td>
<td>Questionnaire</td>
<td>282 patients with cancer</td>
<td>Chi² Spearman’s rho Mann-Whitney U t-test Wilcoxon Logistic regressions</td>
</tr>
<tr>
<td>III. Survey with mixed methods analysis</td>
<td>Questionnaire</td>
<td>231 nonclinical 208 patients with cancer</td>
<td>Logistic regressions Chi² t-test Content analysis</td>
</tr>
<tr>
<td>IV. Psychometric, quantitative, correlational</td>
<td>Screening instruments VAS, HADS, MADRS-S, STAI-S</td>
<td>558 patients with cancer</td>
<td>Correlational analyses ROC curves Chi² t-test</td>
</tr>
</tbody>
</table>

VAS: Visual Analogue Scale, HADS: Hospital Anxiety and Depression Scale, MADRS-S: Montgomery Åsberg Depression Rating Scale – Self-report, STAI-S: State Trait Anxiety Inventory – State.

In Study I, a questionnaire examining the use of the Internet for health-related support was developed through psychometric testing. In Study II, this questionnaire and project-specific questions were applied. In Study III, the same questionnaire was applied with additional questions about preferences regarding Internet-based psychological support as compared to face-to-face support. There were two data collections: one in a nonclinical sample and one in a sample of
patients with cancer. In Study IV, one ultra-short and one short instrument was compared with two longer instruments regarding psychometric properties in online screening for anxiety and depression in another sample of patients with cancer; see Table 1.

Participants
Studies I-III are based on the same sample of patients with cancer but with some differences due to different inclusion criteria in each of the three studies. The eight participants who did the think-aloud interview participated in Study I only. Study IV is based on a different sample than the sample in Studies I-III; see Table 1.

Study I-III
In the first step in Study I, eight participants with a former cancer diagnosis participated in think-aloud interviews. They were engaged in patient organisations and had experience of potential needs for support among people with cancer. The exploratory factor analysis was conducted in one nonclinical convenience sample consisting of staff at two departments at Uppsala University and a rural factory outside Uppsala (n=243). The confirmatory analysis was conducted in a clinical sample of Internet users with cancer (n=215/282). There were 282 patients with cancer and 215 of them reported Internet use.

Study II was conducted in the same sample of patients with cancer as in Study I (n=282). The inclusion criteria were that they were adults (>18 years old) and that they had completed the initial treatment (surgery and/or chemotherapy and/or radiotherapy) or were undergoing either hormone treatment, active surveillance or other treatment. This was to help ensure that the participants had gained perspective on how they had used the Internet immediately after diagnosis and later on. Exclusion criteria were that they did not understand Swedish, were cognitively impaired, and participation in an Internet-based intervention (U-CARE) [95].

Study III is based on the same samples as in study I, the nonclinical (n=231) and the sample of patients previously treated for cancer (n=208). The inclusion criteria were that they were adults (>18 years old) and that they had completed the initial treatment (surgery and/or chemotherapy and/or radiotherapy) or were undergoing either hormone treatment, active surveillance or other treatment. Exclusion criteria were that they did not understand Swedish, were cognitively impaired, participation in an Internet-based intervention (U-CARE) [95], and past or current use of mental health treatments delivered online.
Study IV
This study comprised patients with newly (within 6 months) diagnosed breast, prostate or colorectal cancer and patients with recurrence of colorectal cancer at four hospitals in Sweden (n=558). Exclusion criteria were inability to read and understand Swedish, cognitive disability (such as dementia or psychosis), a constant need of care (Karnofsky score <40), short expected survival (<3 months), severe depression and participation in a competing clinical trial including patients with prostate cancer receiving radiotherapy. The patients in this study were participating in an RCT investigating the efficiency in Internet-administered psychoeducational and psychological support. The data for the fourth study was extracted from baseline data [95]. The overarching goal of the intervention was to promote psychosocial health among patients suffering from cancer by means of self-help programmes delivered via an Internet platform. Following screening to detect levels of patient distress, patients were randomised to standard care or a stepped care intervention.

Data collection and procedures
Study I-III

Questionnaire development – Health Online Support Questionnaire
The HOSQ initially contained 31 questions regarding the incentives for health-related Internet use. The research group developed the questions based on James Houses’ theories on social support, in which he categorises social support into the four classes: informational, instrumental, appraisal, and emotional support, as explained before; informational support is information that is helpful for coping with personal and environmental problems. Instrumental support takes the form of practical help and depends on the limitations of the particular situation and individual. Appraisal refers to information that individuals use in evaluating themselves and emotional support involves empathy, caring, love and trust. The questions asked respondents to provide information on the incentives for health-related Internet use and were all scored on a six-point Likert scale ranging from zero (not relevant/never) to five (on a daily basis). This questionnaire was used in Studies I, II and III. See Table 1 and Appendix.

The face and content validity of the questionnaire was initially tested in eight think-aloud interviews [96]. After minor revisions one nonclinical convenience sample answered the questionnaire. This took place from March to May 2014. The participants in the nonclinical sample were either approached out-
side the food canteen at work (the sample at the factory) or had the question-naire delivered in their mailbox at work (the university sample). This was fol-
lowed by data collection in a sample of patients with cancer who also an-
swered the questionnaire. This took place from November 2014 until February
2015. The participants were handed the HOSQ in the waiting room at the
clinic by research assistants and informed about the study. They could choose
to answer it there or at home and return it by mail.

The data for Studies II and III was collected as described in Study I except for
the think-aloud interviews, which were restricted to the development of the
questionnaire in Study I.

In addition to the HOSQ, the participants also answered project-specific ques-
tions about demographic variables such as age, sex, marital status, birth coun-
try, educational level and whether they had used the Internet during the last
two years, and, in the nonclinical population, whether they had any health
problems. In Study II, the ones who had used the Internet also answered ques-
tions regarding their use of applications (information sites, discussion forums,
blogs, social media and “My Healthcare Contacts”), how often they used them
(0=never, 1=once or twice ever, 2=at least once a year, 3=at least once a
month, 4=at least once a week, and 5=daily or almost daily) immediately after
diagnosis and later on, and how valuable they found them. In Study III, the
participants were asked to indicate which treatment modality they would pre-
fer if in need of psychological help now or in the future: face-to-face, Internet,
both modalities or none. They were also invited to answer open-ended ques-
tions regarding perceived advantages and disadvantages of psychological
treatment via the Internet.

Study IV
The data for this study was collected online from April 2013 until September
2015.

The participants were approached and informed by a research assistant at a
regular visit to the clinic and gave their written informed consent. The partic-
ipants were given written information on how to log on to the portal and of-
fered a demonstration. They were also told that they could call if they needed
support.
**Questionnaires**

**HADS**

The HADS consists of seven questions measuring anxiety and seven measuring depression [97]. The patients were asked to rate their emotional status during the past week on scales graded from 0-3. The total score of each scale is 21 points. A higher score indicates more symptoms. HADS [97] is widely used and the most validated questionnaire in screening for anxiety and depression in patients with cancer [98]. Screening with HADS has been found as feasible for Swedish patients with cancer in identifying patients with psychological distress and has led to increased referral to further assessment and psychosocial support [12].

**VAS**

The VAS measures anxiety and depression on scales ranging from 1 to 100 mm, approximately corresponding to mm on the screen [99]. The patients were asked to grade their levels of anxiety and depression by making a mark somewhere between 0 (no anxiety/depression) and 100 (extreme anxiety/depression) on each scale. Recent research showed that the VAS was less vulnerable to bias from confounding factors, ceiling effects and less time-consuming to answer compared to a Likert scaled questionnaire [100].

**STAI-S**

The STAI-S was used to measure the patients’ state anxiety and as reference. STAI-S comprises 20 items in which the respondents are asked to rate their current feelings on a four-point scale, from *not at all* (1) to *very much* (4). The scores are summed ranging from 20 to 80 [101]. STAI-S is a self-report instrument that has been used online [102] and in many populations and has a well-established internal reliability and criterion and construct validity [103, 104]. The mean score varies between studies and there is no particular cut-off recommended [104-107]. A cut-off level of 39 is used in Study IV based on previous research in similar populations [108, 109].

**MADRS-S**

The MADRS-S was used to measure depression and as reference. The MADRS-S has 9 items [110, 111] and the patients were asked to rate their emotional status during the previous three days. All items range from 0-6 and the total score is 54. A higher value indicates more depressive symptoms. The threshold for depression varies greatly in studies but the cut-offs recommended by Svanborg & Ekselius (0–12 = minimal, 13–19 = mild, 20–34 =
moderate, ≥ 35 = severe) [110] have been used in previous Swedish studies where the instrument was administered both in paper-and-pen versions and online [112-114]. The MADRS-S is an instrument with acceptable psychometric properties regarding validity, reliability and sensitivity to change [115]. Research have shown that it can be transferred to online use without affecting the ability to detect patients with suicidal risk or other psychometric properties in any clinically meaningful way [116]. A cut-off of 12 is used in Study IV [110]

Data analysis

The statistical analyses were performed using IBM SPSS Statistics (version 20.0) [117]; see Table 1.

Study I

Exploratory factor analysis with principal axis factoring was used to investigate the factor structure of the questionnaire. To determine the number of factors to extract, parallel analysis was used. The criteria for retaining an item were (a) a loading >0.30 on either factor and (b) a loading difference >0.15 between the two factors. Items with both factor loadings <0.30 were excluded; see Table 2. To confirm the extracted factor structure, a confirmatory factor analysis was then conducted on data from the group of patients with cancer.

The response patterns in relation to the demographic variables were analysed using the Mann-Whitney U-test and Spearman’s rho since the distributions were positively skewed. This was done on the HOSQ total score, with a maximal possible score (range 0-90) and subscales (range 0-45) calculated.

Study II

To investigate differences between groups, Chi-square tests (sex, education, marital status, treatment and birth country) and t-test (age) were conducted. Differences between the use of applications during the time immediately after diagnose and the time thereafter were conducted with Wilcoxon Signed Rank Test (information sites, discussion forums, blogs). Because of positively skewed data non parametric statistics were used.

Associations between age, gender, education, civil status and completion of treatment and incentives for the use of the Internet (the HOSQ reading, interacting and total scale) were analysed with multiple logistic regression analyses. Due to the data not being normally distributed, the HOSQ scale was dichotomised based on median split to allow regression analysis [118].
Study III

To investigate predictors of treatment preference multivariate logistic regressions were conducted. Due to the data not being normally distributed the HOSQ scale was dichotomised based on median split to allow regression analysis [118]. There was no hypothetical relationship between predictors assumed so a forced-entry approach was applied. Due to a low preference for Internet-based interventions in both samples, the criterion variable was merged into two levels: (1) preference for face-to-face intervention (used as reference category) and (2) preference for Internet or equal preference for both modalities.

Content analysis was applied to analyse the open-ended questions regarding perceived advantages and disadvantages of Internet-based interventions. This is a method to systematically organise and condense data into categories describing a phenomenon [119]. The open-ended answers were regarded as the unit of analysis. Advantages and disadvantages were analysed separately and treated as different content areas. In the first step, the answers were divided into meaning units by one of the researchers. A meaning unit was considered as a part of data that conveyed enough information to provide a sense of meaning. In the second step, the same researcher condensed the meaning units by reducing wording without changing the meaning or core content. An inductive approach was applied to sample 1 (nonclinical) since there were no hypotheses and a deductive approach was applied to sample 2 (patients with cancer) to test the replicability in sample 2 of the categorisation generated from sample 1 [119]. To achieve credibility, three independent coders verified the initial categorisation. Codes placed in more than one or different categories were discussed and revised by the coders to create mutually exclusive categories. Minor changes were made to the categorisation obtained from sample 1. In the final step of the content analysis, categories with similar content were categorised and labelled with an overarching theme. This data was thereafter quantified.

Below is an illustration of advantages and the trajectory from meaning units leading to categories leading to themes. The meaning units to the left were condensed and grouped into categories (in the middle) and thereupon the categories ended up in themes to the right, presented in Figure 2.
Below is an illustration of disadvantages and the trajectory from meaning units leading to categories leading to themes. The meaning units to the left were condensed and grouped into categories (in the middle). Finally, the categories were grouped in themes to the right, presented in Figure 3.
Study IV
To assess the sensitivity and specificity of the HADS and VAS, a receiver operating characteristic curve (ROC) analysis was used with the MADRS-S and STAI-S as references. The ROC curves demonstrate the trade-off between sensitivity and specificity for every possible cut-off score on the VAS and HADS indexes. By calculating the area under the curve (AUC) it was possible to estimate the overall discriminative performance of the VAS and HADS with regard to identification of patients with depression or anxiety symptoms. The AUC can be interpreted as the probability that a randomly selected patient with depression or anxiety according to either the MADRS-S or STAI-S will score higher on the respective VAS and HADS scales than a randomly selected patient without depression or anxiety according to the MADRS-S or STAI-S [120]. An AUC of 0.50 depicts an accuracy no better than chance and 0.70-0.80 represent acceptable discrimination. An AUC of >0.80 represents excellent discrimination and AUC 1.0 depicts a test with perfect accuracy. The sensitivity, specificity, positive predictive value (PPV) and negative predictive value (NPV) were also calculated to establish a relevant cut-off.

Ethical considerations

Studies I, II and III
Asking people with cancer to participate in a study always implies ethical considerations. An important question to consider is whether the questions can cause distress or invade privacy. People may experience distress related to visits to the clinic and asking them to participate in a study may have increased the distress. We asked for behaviours rather than feelings as the risk of emphasising negative thought or feelings was considered low. Another important ethical matter is the one regarding the patient being in a dependent position to those carrying out the research, and thus may find it difficult to say no. The risk of this was also considered low since no one in the research project was involved in the patient care. As there were no obvious benefits to participating in the study, the risk for that as an incentive to participate was considered low. Participation was voluntary and could be stopped without any explanation. The questionnaires were fully anonymous, treated confidentially and presented at a group level. We do believe that greater knowledge about how the Internet can contribute as a source of support is beneficial for patients, the healthcare system and the society. Ethical approval was granted by the Regional Ethical Review Board in Uppsala (2013-11-20; reference number 2013/436). Consent to participate was implied by the completion and return of the questionnaire.
Study IV

Ethical approval was granted by the Regional Ethical Review Board in Uppsala (Ref. no. 2012/003). Written informed consent was obtained from the participants before inclusion. The respondents participated in an intervention study and extensive measures were taken, and will continue to be taken, to minimise the risk of infringing activities and to ensure that study participants’ personal data cannot be linked to patient-reported data by unauthorised persons. Asking people about their mental state may be troublesome for some people because it emphasises potential psychological consequences of cancer. On the other hand, it can be helpful and provide a sense of legitimation and room for the psychological aspects of the disease. The main ethical risk is including participants with a need for other specialised medical care, such as those with severe depression. The baseline measurement is designed to minimise that risk. All study participants were also planned to have an established contact with physicians in routine healthcare. By learning more about the efficiency of Internet-administered psychosocial screening methods, we may be able to incorporate systematic screening that saves time and effort for both patients and staff.
Results

Summary of findings

Study I
The HOSQ was found suitable as a generic questionnaire which can be applied to various groups with health problems and sickness. The final factor loadings accounted for 45.3% of the variance. The EFA on the final 18-item scale resulted in 2 factors (Table 2). After analysing the content of the factors they were labelled “reading” (nine items) and “interacting” (nine items). Both factors demonstrated good internal consistency (Cronbach alphas .88 and .77, respectively). Following the initial analysis, the factors were confirmed in the cancer population. The response pattern demonstrated expected differences both between the interaction and reading scales and according to demographical variables such as gender, age, education, and health problems. These findings were regarded as supporting the validity of the HOSQ.

The mean value in the nonclinical sample (n=229) was 11.95 (standard deviation (SD) =9.1) for the total score, 9.13 (SD=6.5) for the reading subscale and 2.84 (SD=3.9) for the interacting subscale.

The scale initially consisted of 31 items, which was then reduced to 18 items according to certain criteria. The criteria for retaining an item were (a) a loading >0.30 on either factor and (b) a loading difference >0.15 between the two factors. Items with both factor loadings <0.30 were excluded (Table 2).
Table 2. A schedule on the incentives for removing and maintaining the initial 31 items. The items in bold font are the maintaining items. The right two columns contain the factor loadings of the exploratory factor analysis (EFA) of the final 18-item version of the Health Online Support Questionnaire (HOSQ) in the nonclinical group (n=229).

<table>
<thead>
<tr>
<th>Items</th>
<th>Restricted response width</th>
<th>Factor loadings ( \Delta &lt; .30 ) and ( \Delta &gt; .15 )</th>
<th>Factor loadings ( \Delta &lt; .30 )</th>
<th>Content mismatch</th>
<th>Overlap and equalisation</th>
<th>Factor 1 reading</th>
<th>Factor 2 Interacting</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. To search for information that can improve my health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.616</td>
<td>0.034</td>
<td></td>
</tr>
<tr>
<td>2. To feel that I’m not the only one with this type of health situation</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. To search for information about psychological support</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. To feel that there is someone who is interested in my thoughts and feelings</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. To search for information about how to change unhealthy behaviour</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. To share information about a disease treatment that I’ve been through</td>
<td></td>
<td></td>
<td></td>
<td>-0.083</td>
<td>0.393</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. To buy medicine, vitamins, supplements, alternative medicines, etc.</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. To express my thoughts and feelings anonymously</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. To read about other people’s experience of disease/bad health/a treatment</td>
<td></td>
<td></td>
<td></td>
<td>0.502</td>
<td>0.198</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. To order books about my illness/health condition</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Description</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>-----------------------------------------------------------------------------</td>
<td>---</td>
<td>---</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>To be able to make more well-informed decisions regarding my health</td>
<td></td>
<td>0.720 0.065</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>To stay in touch with friends and colleagues when I’m sick or not feeling well</td>
<td></td>
<td>0.078 0.598</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td>To share practical advice and suggestions regarding my health</td>
<td></td>
<td>-0.054 0.685</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>To handle administrative matters relating to my illness/health (e.g., sick leave)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>To order equipment, assistance, medical travel, etc.</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>To search for information that enables me to better understand physicians and other health staff</td>
<td></td>
<td>0.528 0.083</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>To search for encouragement from others when I’m stricken by disease or not feeling well</td>
<td></td>
<td>-0.070 0.690</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18.</td>
<td>To express my opinion regarding health/disease/care</td>
<td></td>
<td>0.043 0.420</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19.</td>
<td>To search for information from different sources to enable the best care</td>
<td></td>
<td>0.730 0.085</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20.</td>
<td>To search for compassion when I’m not feeling well</td>
<td></td>
<td>0.093 0.445</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21.</td>
<td>To meet others in a similar health situation</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22.</td>
<td>To get feedback from people who have, or have had the same health problem as I have</td>
<td></td>
<td>0.137 0.443</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Statement</td>
<td>Factor Membership</td>
<td>% Variance</td>
<td>Cronbach’s Alpha</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>-------------------</td>
<td>------------</td>
<td>------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23. To search for scheduled appointments, addresses or phone numbers to healthcare providers</td>
<td></td>
<td>0.619</td>
<td>0.88</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24. To seek confirmation from others that my health-related decisions are good</td>
<td>X</td>
<td>-0.017</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25. To search for information when I feel worried</td>
<td></td>
<td>0.763</td>
<td>0.77</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26. To keep friends and relatives informed on how I feel</td>
<td></td>
<td>0.030</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>27. To get feedback from friends and relatives on how I’m handling my health situation</td>
<td></td>
<td>-0.038</td>
<td>0.88</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>28. To search for the latest research regarding my health situation</td>
<td></td>
<td>0.647</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>29. To seek financial support on account of my illness/health condition/care (medical insurance, benefits, funds, etc.)</td>
<td>X</td>
<td>-0.045</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30. To obtain personal advice as to how I should handle my health situation</td>
<td>X</td>
<td>0.890</td>
<td>-0.116</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>31. To find out whether symptoms that I’ve experienced are dangerous or not</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Bold font indicates factor membership.
Study II

Two hundred and fifteen (76%) of the participants were Internet users and to a greater extent were younger, cohabitated and had a higher education than the group of nonusers. Among the Internet users, the most common types of cancer were prostate and breast cancer and the median time since being diagnosed was three years (range: 48-0 years).

Among the Internet users, 77% reported that they had used the Internet to search for health information since receiving their diagnosis. Thirty eight percent reported use of “My Healthcare Contacts” and 18% had been accessing information and test results in the electronic medical record, 4% had scheduled appointments, 6% had renewed prescriptions, 2% had chosen GP, and 0.5% (one person) had been accessing psychological treatment on the Internet. Thirty four per cent reported use of social media, 21% had visited health-related discussion forums and 18% had visited blogs.

Internet users more often searched for information immediately after diagnosis compared to later on (information; \( p < .000 \)). No differences were found regarding the use of other applications (forums, blogs) during the time immediately after and thereafter. A vast majority of those visiting information sites (86%) and discussion forums (81%) did it regarding their own health. The use of the other applications was less related their own health (blogs: 58%, social media: 28%). The use of applications was graded on a scale from one to ten and the use of “My Healthcare Contacts” was considered the most valuable (mean: 6.7; SD=3).

The multiple regression analysis showed that a lower age predicted a significantly higher use of the Internet to search for health-related information and interactive support. Having a university degree predicted a significantly higher score on both subscales and the total scale, implying more use also of health related interactive support. Completion of treatment predicted a significantly lower score on the information-seeking subscale, which implies more use of the Internet to search for information immediately after diagnosis.

Study III

A majority of the participants in both sample 1 (nonclinical) and sample 2 (patients with cancer) reported that they would prefer psychological interventions face to face if they were in need of psychological treatment (Table 3). In sample 2, individuals born outside Sweden were more likely to prefer Internet-based interventions (IBI) compared to individuals born in Sweden. Participants who reported use of the Internet to search for and read health-related information were more likely to prefer IBI or both forms, in both sample 1 (odds ratio [OR] 2.82, 95% CI 1.18-6.75) and sample 2 (OR 3.52, 95% CI
The reported advantages and disadvantages were similar in both samples. Internet-based interventions were perceived as advantageous due to flexibility regarding time and location, accessibility, low effort, anonymity, credibility, user empowerment, and improved communication between therapist and client; see Figure 4. The perceived disadvantages reported were impoverished communication between therapist and client, concerns about confidentiality, requirements of computer literacy, low credibility, fear of negative side effects, and anonymity; see Figure 5.

Table 3. The preferences for psychological treatment forms in the participants with or without cancer

<table>
<thead>
<tr>
<th></th>
<th>Sample 1 nonclinical n=154</th>
<th>Sample 2 Patients with cancer n=189</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological intervention</td>
<td></td>
<td></td>
</tr>
<tr>
<td>face to face (FF)</td>
<td>103/154 66.9%</td>
<td>123/189 65.1%</td>
</tr>
<tr>
<td>Internet-based psychological</td>
<td></td>
<td></td>
</tr>
<tr>
<td>intervention (IBI)</td>
<td>10/154 6.5%</td>
<td>5/189 2.6%</td>
</tr>
<tr>
<td>Both FF and IBI</td>
<td>32/154 20.8%</td>
<td>41/189 21.7%</td>
</tr>
<tr>
<td>None of the formats</td>
<td>9/154 5.8%</td>
<td>20/189 10.6%</td>
</tr>
</tbody>
</table>
Figure 4. Reported perceived advantages of psychological treatment online among participants in sample 1 = nonclinical, and sample 2 = patients with cancer

Figure 5. Reported perceived disadvantages in psychological treatment online among participants in sample 1 = nonclinical, and sample 2 = patients with cancer
The themes and categories that summarize the reported perceived advantages in psychological treatment online in *Figure 6.*

![Diagram](image)

Figure 6. The reported advantages from categories to themes
The themes and categories that summarize the reported perceived disadvantages in psychological treatment online in Figure 7.

![Diagram showing the reported disadvantages from categories to themes]

**Study IV**

In our sample the MADRS-S identified 107 cases (19%) and 444 non-cases of depression and the STAI-S identified 165 cases (30%) and 385 non-cases of anxiety.

By comparing the ultra-short VAS anxiety and depression scales and the short HADS with the two longer reference instruments STAI-S and MADRS-S using recommended cut-offs as a reference, the VAS and HADS were found as comparable to the longer questionnaires regarding the ability to discriminate between persons with and without clinical levels of symptoms of anxiety and depression, respectively; see Figure 8-11.
The ROC curves depict the balance of sensitivity and specificity. Based on a trade-off of these values as well as positive predictive values (PPV) and negative predictive values (NPV), optimal cut-offs for the HADS and VAS anxiety and depression scales were identified.

Figure 8.
HADS anxiety: AUC = 0.9

Figure 9.
VAS anxiety: AUC = 0.90

Figure 10.
HADS depression: AUC = 0.94

Figure 11.
VAS depression: AUC = 0.88
For HADS Anxiety, a cut-off of 6 had a sensitivity of 88% and a specificity of 81%. The PPV was 75% and NPV 90%. For VAS Anxiety, a cut-off of 7 mm had a sensitivity of 86% and a specificity of 83%. The PPV was 70% and NPV 93%. For HADS Depression, a cut-off of 5 had a sensitivity of 91% and a specificity of 83%. The PPV was 66% and NPV 97%. For VAS Depression, a cut-off of 7 mm had a sensitivity of 85% and a specificity of 83%. The PPV was 56% and NPV 95%. 
Discussion

Main findings

The main findings of the studies in this thesis showed that the interest in many forms of Internet-administered support was generally low in patients with cancer. The patients who reported using eHealth mostly did this to search for information, whereas search levels for interactive support were low. “My Healthcare Contacts” (Mina vårdkontakter), where patients can e.g. access their medical records and schedule appointments, was considered the most appreciated tool. Persons in the nonclinical and clinical sample who already used the Internet to search for health-related information stated that they would be more likely to accept Internet-based psychological interventions if they were in need of psychological treatment. The vast majority in both samples, however, reported that they would prefer psychological support face to face. Among patients with cancer, those born abroad were more likely to report that they would prefer face to face delivered and Internet-delivered psychological interventions equally if they were in need of psychological support.

Another main finding was that the HOSQ showed good internal consistency, similar factor structure and salient Internet behaviours, in both the nonclinical and group of patients with cancer, and hence may be used as a generic questionnaire regarding health-related Internet use. It captures interactional and/or reading behaviours in various groups with health alterations. The response pattern also revealed expected differences both between the interaction and reading scales and according to age, gender, education and health problems, which can be considered to support the validity of the HOSQ.

The online-administered HADS and VAS anxiety and depression scales were found comparable to the longer instruments MADRS-S and STAI-S regarding the ability to discriminate between persons with and without clinical levels of symptoms of anxiety and depression. At certain cut-offs, the HADS and VAS identified patients with anxiety and depression symptoms with high accuracy.

HOSQ

Study I showed that the HOSQ had the ability to tap useful information on the search for health-related support online. The questionnaire ended up with a
meaningful two-factor structure with good internal consistency. The two factors that appeared in the EFA represented reading versus interactive e-health behaviours. This structure was then confirmed in a CFA in a second population with cancer and hence considered to be robust.

The HOSQ-structure

It was initially thought that the four classes of social support suggested by House [24] could appear as four factors. The EFA found the two factors of interaction and reading and a plausible explanation is that the two factors tapping reading and interaction are more salient, although the four categories of support described by House may be embedded in the two factors that appeared. According to the UTAUT, the usefulness (performance expectancy) and social influence correlate with the willingness to use IT. The scales and pattern in our findings support this theory. Research has repeatedly shown that patients with cancer find informational support important [26, 28] and performance expectancy may thus be a strong incentive to use eHealth. In order to stay updated, participate in the care and make informed decisions, the patients may need information that can be found on the Internet. The response pattern to the scales revealed expected differences regarding gender, age, education and health problems and between the scales. The participants who were younger, had higher levels of education and reported health problems reported more use of the Internet for health-related purposes. This is also in line with the UTAUT, in which gender and experience have been found as moderators to the use of IT [92].

In the initial version of HOSQ, containing 31 items, there were also questions on instrumental support but many of these were removed in the final version due to poor correlation with the two factors derived. The importance of instrumental and other forms of support should however not be overlooked among individuals with health alterations and severe diseases such as cancer. A qualitative study focusing on patients with cancer and different coping strategies found that the need for support varied during the disease trajectory and that the patients emphasised not only a need for informative, emotional and interactive support but also for instrumental and spiritual or religious support [121]. The development of the HOSQ revealed that informational and interactive support are two salient incentives for the use of eHealth but there is a possibility that there are other salient incentives as well and that the HOSQ did not tap that. The UTAUT supports the salience of the scales since performance expectancy and social influence are the two factors that correlate the most with the willingness to use IT. The search for information is manifested in the reading scale and the search for interaction is manifested in the interactive scale.
Reported eHealth activities

The proportion of participants in Studies I-III who reported use of eHealth to search for information was much larger than the one reporting use to share information. This could be related to both performance expectancy and effort expectancy since reading only may take less of an effort than also sharing. In a large American survey on people with chronic illness and Internet use, about one-third reported that they accessed health information online by reading other people’s comments on medical/health experiences on websites, blogs or online newsgroups [58]. Of those, only 6% reported that they also posted health-related comments themselves. Those who interacted and shared knowledge and experiences with others were a minority compared with those who read what other people shared [58]. Research has shown that people who share information seem to benefit more from online social support groups and that they report a higher mental wellbeing than those who don’t share [122, 123]. It is difficult to tell whether the “sharing behaviour” leads to higher wellbeing or if it is the other way around, and wellbeing instead reinforce a “sharing behaviour”. This needs further research and the HOSQ may be used to find out whether individuals or groups tend to be primarily interested in reading only or also in interacting, together with instruments measuring wellbeing and other variables. Investigating how these different behaviours correlate may provide valuable information for enhancing tailored and adequate support online.

The use of “My Healthcare Contacts”, which involves accessing information and test results in the electronic medical record was considered the most valuable application. This result corroborates other research showing that a majority of patients with cancer consider improved access to their medical records as something that should be prioritised [26]. Scheduling appointments, renewing prescriptions and choosing GP were also reported and these may be highly efficient eHealth tools for patients to increase their ability to be self-efficient as well as reduce the workload in the healthcare system [124]. The use and appreciation of “My Healthcare Contacts” can be explained by performance expectancy as access to the electronic medical record enhances the ability to stay informed and participate in the treatment and care decisions.

The use of blogs and discussion forums was relatively low and among those who used social media, the majority of the visits were not related to their health situation. Our findings also showed that the participants who reported having a health problem searched for health-related information and interaction to a greater extent than participants who did not report a health problem. This finding also corresponds with the UTAUT [92], in which usefulness has the highest influence on the possibility that an individual will take on and master a new IT system. However, other research has shown the opposite, that
those who reported having health problems used the Internet for health purposes less than those who did not report health problems [62]. A plausible explanation could be that there are cultural differences in that the threshold for health-related Internet use is higher in countries where access to the Internet is relatively low, and correlated to a higher socioeconomic status and better health. In Sweden, more than 90% of the population are Internet users and approximately 90% of the population over the age of 12 have access to the Internet at home [125], which makes Swedes one of the most Internet-using people in the world and thus results should be interpreted in light of that fact. It is therefore also important to further examine cultural differences regarding eHealth. Many people today use the Internet as a tool to help themselves (and others) better understand and handle perceived health challenges. By considering factors such as ease of use, usefulness and social impact, the rate of the adoption of health information technology can be increased [126]. Nevertheless, one should have in mind that even though the Internet may be a multifaceted facilitator of support it is not certain that everyone benefits from using it. Solutions on how to reach out to patients with various forms of support that enable participation in treatment and care decisions may be crucial to enable self-efficacy and patient empowerment.

Demographic variables and use of eHealth

Studies I, II & III showed that there were differences regarding demographical variables. Women seemed to use the Internet for health-related purposes, and especially for interaction, more than men. Other research corroborates these findings, showing that women tend to be more willing to seek health information online, figure out a possible diagnosis and use social media and blogging for this purpose, and women also have lower dropout rates in online self-help interventions [70, 125, 127, 128]. We also found differences regarding age. In the nonclinical as well as the clinical sample, younger people reported that they used the Internet for health-related purposes more often than older people. Other research confirms the pattern that Internet use is not as high among older adults as for the younger. However, Internet use is increasing among older people as well, internationally and in Sweden [70, 125, 129]. Health activities online were positively influenced by having a university degree. Our findings might indicate that the threshold to health-related activities online is higher for the older and less educated individuals and thus needs to be further addressed. Study III showed that patients born abroad were more likely to prefer face to face and Internet-based psychological interventions equally. The group of participants born abroad in our study was too small to draw any certain conclusions, though. According to the UTAUT, age, gender and experience are moderating factors for the use of IT and social influence a
factor that correlates highly with the willingness to use IT. All the results regarding demographical variables correspond with the theoretical framework of the UTAUT [92] and can be explained from the perspectives of this theory.

Attitudes towards psychological interventions online

The most salient advantages regarding Internet-based interventions, reported in Study III, were the flexibility regarding time and location, accessibility, low effort, anonymity, credibility, user empowerment and improved communication. The disadvantages reported were low credibility, anonymity, impoverished communication, negative side effects and computer literacy/safety concerns. These results are corroborated by similar findings in former research [130-132]. Anonymity and credibility were reported as both disadvantageous and advantageous. This may be explained by differences between individuals in preferences regarding integrity and communication. There may be individuals who experience a stronger sense of support in communication face to face because of personality traits or preferences. There may also be individuals who dare to seek support only if they can be anonymous who find Internet-based support highly suitable and efficient. This needs to be thoroughly studied though to draw any conclusions. In our study the reported advantages and disadvantages were hypothetical, which may have affected the results. If the respondents would have been in actual need for psychological treatment, they may have reported differently. More research is needed to be able to tell whether that is the case. These findings can also be explained by the UTAUT since the use of IT is highly correlated to social influence, so anonymity is thus an incentive to use IT for some individuals and a hindrance for other individuals.

However, despite the increasing evidence for the efficacy of electronic psychological help interventions, the transition and implementation of these into clinical practice is slow. A recent study in the UK showed that the belief in Internet-administered psychological health interventions was low. Most of the factors that were rated as important for the decision to engage in mental health programmes were not expected in computerised treatments as opposed to face-to-face-delivered treatments. Convenience of access was the only domain in which computerised treatments scored higher than treatment face to face. The likelihood of using computerised treatments was therefore reported as low. The researchers conclude that policymakers need to improve the public perception of these interventions in order to achieve a successful implementation [132]. Research shows that the expectancy on how beneficial a system can be predicts the willingness to make an effort to learn how to use it and that experience moderates the willingness to use IT [57]. This supports the conclusion that policymakers need to find ways to reach out with information on how to use different systems and their efficiency. That may change the perception of
both performance expectancy and effort expectancy among potential stakeholders.

Psychological distress and screening in patients with cancer

The prevalence of both anxiety and depression in our study was higher than in some other studies in similar samples [6, 10]. A plausible explanation is that a majority of the participants in study IV were under treatment. The prevalence of anxiety and depression in patients with cancer varies greatly across studies because of the different characteristics, length, cut-off and psychometric properties of the instruments as well as the cancer stage, phase and response to the treatment [6]. Recent research showed that depression occurred more often in patients receiving chemotherapy than in those who did not. The risk of depression was also shown to be higher during the first year after diagnosis and the individuals receiving chemotherapy had higher levels of depression than the ones who did not. Adverse symptoms of the treatment were also shown to be associated with increased levels of depression and decreased health-related quality of life [133]. It is important to consider results from the perspectives of disease and treatment state, phase and responses since these factors may influence both physical and psychological conditions. It is also important to consider results from the perspectives of psychometric properties of the screening instruments employed.

Efficiency of the short HADS and VAS anxiety and depression scales in screening

For VAS Anxiety, a cut-off of 4-8mm identified a large majority of the patients with symptoms of anxiety and ruled out a majority of the patients without symptoms. Only a few of the patients with symptoms remained undetected. A cut-off of 5 on HADS Anxiety identified almost all the patients with symptoms and failed to detect only a few. Former research in a similar Swedish setting found that a cut-off of ≥4 at HADS was optimal in order to detect the unstable patients who deteriorated in their psychological health and quality of life during the disease trajectory [40, 134]. Study IV showed that the prevalence of anxiety was higher than the prevalence of depression, which is corroborated by other research showing that the incidence of anxiety is higher in cancer settings [10, 135]. The prevalence of anxiety varies across studies [6, 10]. In one study on a large heterogeneous sample, the incidence was 23% [136] and in other studies in similar samples the prevalence varied between approximately 12-50% [10, 135, 137]. Based on one of their meta-analyses, the researchers argue that anxiety rather than depression is a problem in long-term cancer survivors, and as such, efforts should be made to improve recognition and treatment of anxiety in this group [10].
A cut-off at a score from 4 to 7 on VAS Depression identified a large majority of patients with symptoms. A cut-off score of 4 is preferable as an initial step in a screening procedure since it has the highest ability to identify a patient with depression symptoms and the lowest likelihood of failing to detect individuals with symptoms of depression. A cut-off at a score of 5 or 6 on HADS depression identified a large majority of patients with symptoms. A cut-off score of 5 is preferable as an initial step in a screening procedure since it has the highest ability to identify a patient with depression symptoms and the lowest likelihood of failing to detect individuals with symptoms of depression. Previous research has recommended even lower cut-offs when screening for emotional distress in patients with cancer [138, 139]. The HADS is the most thoroughly evaluated measure of depression in oncology settings but due to the variety of cut-offs there are difficulties in comparing the findings. Another reported limitation is that the HADS has a relatively low acceptability in clinical settings due to its length and scoring system [140]. This problem could be reduced by computerisation and automation when administered online.

**The shorter VAS and HADS versus the longer instruments MADRS-S and STAI-S**

The findings in Study IV indicate that the VAS and HADS have approximately the same accuracy as longer instruments in identifying patients with anxiety and depression symptoms. Since the shorter screening instruments are usually less time-consuming and less demanding, the VAS and HADS are suggested in the initial step in a screening process. Other research corroborates that the HADS is a suitable instrument for initial screening on anxiety and depression but that it cannot be recommended as a diagnostic instrument [141, 142] even though it has been suggested as a case finding follow-up instrument as well [143]. The VAS has shown good psychometric properties when evaluated and compared to STAI; findings suggest that it is perceived to be easy to complete and that it adequately measures anxiety [144]. Other research has shown that the VAS is better at avoiding confounding factors and ceiling effects and is less time-consuming as compared to a Likert scale questionnaire [100]. According to the UTAUT, the expectancy on how much effort that has to be put in (effort expectancy) influences the willingness to use IT. Implementing shorter and less time-consuming online instruments that are automated may increase the screening adherence. Many Internet-administered instruments are paper questionnaires that have been adapted for online use. Research has shown that many paper and online versions of the same instruments correlate to a high extent but that differences such as mean scores and psychometrics do appear [145]. It is therefore crucial to further investigate the validity and reliability of Internet-administered questionnaires that have been adapted from paper-and-pen versions. The optimal solution may be to develop new screening instruments online which should be considered in future research.
Methodological considerations

The ambition of this thesis was to develop a questionnaire measuring health-related Internet use, examine the use and preferences of health-related Internet use and to investigate whether the ultra-short and short instruments VAS and HADS respectively have the psychometric properties to be applied in online screening for emotional distress in patients with cancer. To answer these questions, data was gathered in four studies and analysed using primarily quantitative methods, except for in Study III, where mixed methods were applied. However, methodological considerations and limitations in the four studies need to be discussed.

Study I-III

The heterogeneity in the sample of patients with cancer was satisfactory. Both regarding diagnosis, age, sex and educational level. The results may thus be fairly representative for people with cancer but limited to the group that have completed the initial treatment. Moreover, there is a chance for recall bias since the estimated median time since diagnosis was three years. There is a chance that the reported frequency of Internet use is over- or underestimated, which decreases the reliability of the findings.

Study I

In Study I, we initially conducted an EFA that was confirmed by a CFA. The CFA can only be applied to compare different models, and as such, the results of the CFA should be interpreted with caution. However, the CFA showed adequate model fit and there was no indication that the model could be further improved. The sample size used in the CFA was a bit small but the model was considered simple enough to allow for analysis. However, the factor structure should be confirmed in future studies in other and larger samples. The questionnaire was tested in convenient samples and caution should thus be taken in generalising the findings. We did test it in three samples though; one without health problems, one with minor and one with severe health problems, and the same two factors appeared. Thus, the HOSQ may be used a generic questionnaire examining the use of health-related support on the Internet in groups with various forms of health problems.

Regarding content validity, we could have used focus group interviews with key informants in the development process of the questionnaire. That could have contributed to the selection of questions. However, the think-aloud interviews with did not indicate that there was a lack of relevant aspects and the content validity can thus be assumed as fairly good. The construct validity also needs further evaluation. Our study showed expected patterns regarding the use of the Internet to search for information and health-related and demographic variables [70], but since the HOSQ also measures other types of
support, the “known group validity” cannot be applied. Regarding reliability, we only administered the questionnaire once. On the other hand, a test-retest would have been problematic since we asked for behaviour which could have been influenced by altered behaviour between the two observation points. It is therefore important to test the questionnaire in other groups in future research.

It was difficult to assess the response rate in the nonclinical sample since it was partly administered by mail. The vast majority in both groups answered the questionnaire though, and it may therefore be assumed that the questionnaire was fairly easy to answer. There was a preponderance of men in both groups and in the nonclinical group a majority were well-educated. Among the women, a majority were well-educated in both groups. This may have led to higher scores than what can be generalised to online users in general. Well-educated people are more frequent Internet users [26, 70], though this may change over time.

Study II
During the inclusion of patients to Study II, many of the patients who declined participation said that they did not use the Internet. There may therefore be a larger proportion of Internet users in our study than what is representative for the population examined. The participants’ definition of the time immediately after diagnosis varied greatly, and as such, the results regarding the need for information during the time immediately after compared to later on should be interpreted with caution. The questionnaire used in Study II had not been used before, so the validity and reliability of the questionnaire is uncertain. It was initially psychometrically tested and validated in two samples, however, and was considered to have a fairly good face and content validity [146]. According to the UTAUT, there are variables that potentially mediate the use of technology, which have not been collected or analysed in this study [92]. It should be kept in mind that there may be other factors than those collected that may have influenced the findings in this study. The HOSQ was dichotomised, which reduces the variability of continuous variables.

Study III
A large number of participants did not respond to the question on treatment preferences, which may reflect a systematic bias in which the participants with a negative view on psychological treatments chose not to answer the survey. Moreover, the answers to the open-ended questions were sometimes narrow and incomplete, which may have led to some misinterpretation and thus affected the credibility and transferability of the categorisations of advantages and disadvantages. If in-depth interviews would have been applied instead, the risk of misinterpretations may have been avoided to a higher extent. Another important fact is that the answers on preference were hypothetical. It is
possible that the answers would have been different if the participants would have experienced an actual need for psychological treatment. Moreover, the HOSQ was dichotomised in the regression analysis, which reduces the variability of continuous variables and may hide differences on a more detailed level.

The trustworthiness in the content analysis can be assessed from the perspectives of transferability, dependability, confirmability and credibility [147]. These four interrelated concepts can be defined as the qualitative equivalents of the quantitative concepts generalisability, reliability, objectivity and validity. The extent to which our findings are transferable to other groups can be understood by the transparent description of the participants, procedure and setting. The level of dependability was fairly good due to the process of analysis, in which the three researchers independently categorised the meaning units and discussed the labels of the themes repeatedly through the process. Confirmability can be referred to as the neutrality of the data and that the perception of the information given by the participants is not biased by the understanding of the author. To control for this, the three researchers assessed and discussed the understanding of the data repeatedly, both blinded and open. Most of the time the researchers agreed and otherwise the discrepancy was scrutinised until consensus was reached. Credibility can be referred to as the confidence in the truth and interpretation of the data. Since open questions were used rather than interviews, there is a chance that the answers were shallow and that there was not enough room for participants to give the whole answer. The researchers tried to control for this by discussions regarding the topic and literature review. The findings did not deviate compared to similar studies, which may be a sign that the interpretation was biased by prior assumptions. On the other hand, it could also be a guarantee for credibility since the same construct has appeared and been perceived before. Moreover, the credibility may have been strengthened through focus group- or in-depth interviews with the participants since the risk of misunderstandings may have been lower.

**Study IV**

The findings in Study IV are based on a sample of newly diagnosed patients with breast, prostate or colorectal cancer or a colorectal cancer relapse and therefore not representative for long-term survivors or other cancer diagnoses. However, the sample in this study consisted of patients with both curable and non-curable disease and may therefore be applied to a larger group of patients than the sample applied. Furthermore, the findings are based on baseline data in a quite demanding longitudinal intervention study, and the participants were thus not asked to answer questionnaires at one single observation point but in many. There is a chance that the participating patients had a higher wellbeing than the patients who declined participation. The motivation to participate in
the quite demanding online intervention study that follows the baseline data collection applied in our study may correlate with better psychological and overall health conditions. There is a chance that this affected the sample and the number of non-participants and withdrawals (n=939). Thus, future studies designed to compare online instruments have to be conducted to confirm our findings. There is a chance that there may have been a problem with face validity in the online version of the VAS since the mean score was relatively low compared to paper-and-pen versions [99]. Nevertheless, when comparing the value received from the VAS to the one gathered via other answer scales in Internet studies, mean ratings for assessed VAS have been shown to be equal [148]. The choice of endpoints is another plausible explanation, the expressions “Anxiety” and “Depression” were applied, which may have been interpreted as relatively severe conditions compared to “worry” and “feeling down”, expressions more commonly used in Swedish. This may have resulted in a higher number of true positives but also to more undetected patients with symptoms. To be able to draw any certain conclusions, this needs to be further investigated. The choice of the MADRS-S and the STAI-S as reference instruments is not beyond criticism since they are not the most validated instruments in cancer settings. Nevertheless, they have both demonstrated good psychometric properties in various studies and different settings, including cancer and in online settings [102, 116, 149]. The choice of MADRS-S as a reference questionnaire for depression was primarily based on the following factors: it has consistently shown a satisfying inter-format reliability in high-quality studies comparing the online version with a paper-and-pen version [145]; it correlates highly with a widely used and evaluated instrument, Beck Depression Inventory (BDI), which has demonstrated excellent sensitivity and specificity in a majority of studies regarding the detection of any depressive disorder [46, 150]; and it has shown better psychometric properties regarding the ability to identify suicidal patients than the BDI, in an online psychometric comparison study [116]. Thus, the MADRS-S can be used with confidence in an online context and was thus chosen as a reference questionnaire in the present study. The choice of STAI-S was based on the fact that it is a widely accepted self-reporting instrument, has a well-established criterion and construct validity and internal reliability coefficients, and has been used in many populations [103, 104]. The choice of self-report measures instead of in-depth interviews to establish the expected prevalence of anxiety and depression as well as relevant cut-offs is not optimal. Results should therefore be interpreted with caution.

Conclusions
Findings from Study I showed that the HOSQ might be a reliable and valid instrument for measuring the use of online support for people with health
problems and diseases such as cancer. Findings from Study II confirmed results from other studies showing that people with cancer turn to the Internet primarily for informational support that enables them to influence their care and to stay in touch with friends and relatives. Demographical differences regarding the uptake of Internet-administered support remains, which indicates a need for research on how to bridge the digital gap. By learning more about the use of eHealth among people with cancer, the possibility to provide adequate support may increase. Findings in Study III showed that the vast majority would prefer psychological treatment face to face rather than Internet-administered psychological support if they were in need of support. Findings from the content analysis suggest that Internet-based interventions have specific advantages that may facilitate help-seeking among some individuals and some disadvantages that may be perceived as barriers by the same or other individuals. Findings in Study IV showed that the use of the short and ultra-short tools HADS and VAS may be suitable in the initial step of online screening in busy clinical settings. However, there is still a large proportion of patients who lack the interest or eHealth literacy to use Internet-administered support. There is a need to find solutions for this group in order to identify all the patients with psychological distress or other health-related problems and to provide adequate support.

Research and Clinical implications

Our results corroborate other findings on the correlation between higher age and less interest in eHealth, which may be one of the most pivotal challenges on both organisational and clinical levels in the implementation of eHealth. According to the SKL and vision 2025, Sweden is predicted to be world-leading in eHealth in the near future. Since authorities have expressed expectations regarding eHealth solutions with the aim of equity in care, future research should focus on the perceived barriers to eHealth among older and less educated people who on a group level may be individuals with the biggest needs for various types of support. By developing and implementing eHealth learning programmes there is a chance to bridge the gap between what is expected regarding the level of participation in care and self-efficacy and the barriers to using eHealth. The HOSQ may be used in future research regarding the use of different kind of support and as a basis for the development of different forms of support on the Internet. The reported preferences and the advantages and disadvantages regarding Internet-based psychological interventions may be used to customise interventions and in initiatives to increase treatment acceptability. Our findings regarding the psychometric properties of the online versions of the HADS and VAS, for screening for anxiety and depression, have contributed to the knowledge on efficient screening methods. Future studies on the performance of the online versions of the HADS and VAS should, how-
ever, be further tested among patients with cancer and other diagnoses. Psychometrically sound and time-efficient screening instruments are crucial in order to increase screening adherence in busy clinical settings and offer support accordingly. The clinical acceptability of routine screening may increase if screening instruments are computerised and automated which reduces the workload. Future research should also focus on the use of My Healthcare Contacts and whether the access to the electronic medical record is beneficial and enables patient empowerment and self-efficacy. Research has repeatedly shown that the higher the expectancy on how helpful a system is perceived, the more likely the willingness is to use it. The use of eHealth may be a highly efficient tool for patients to stay informed, schedule appointments and communicate with healthcare and thus achieve self-efficacy and increase patient empowerment. Nevertheless, there may be people who need support face to face despite performance expectancy and experience. Our findings as well as former research show that a majority prefer psychological interventions face to face. If that can be explained by societal or habitual factors, or if there are components in face-to-face support that cannot be replaced in Internet-based interventions, this is a question for future research to answer.
Svensk sammanfattning

Bakgrund

Förekomst av ångest och depression är inte ovanligt hos personer som diagnoseras med cancer och varierar beroende på cancerdiagnos, sjukdomsfas, kön, ålder och val av screening-instrument. Ångest och depression hos personer med cancer är associerat med nedsatt hälsorelaterad livskvalitet och sämre prognos och följsamhet i behandling. Det är därför viktigt att identifiera de patienter som lider av ångest och depression och erbjuda stöd för att förebygga bestående psykisk ohälsa.

Behandling av cancer ges idag i regel polikliniskt vilket innebär att patienter tillbringer allt mindre tid på sjukhus tillsammans med personal och medpatienter. Detta kan vara fördelaktigt för patienter som inte behöver tillbringa lika mycket tid på sjukhus som tidigare men det kan också innebära en minskning av olika former av stöd som tillhandahålls av personal och medpatienter. Parallel med denna ökning av poliklinisk behandling förväntas patienter vara allt mer självbestämmande och deltagande i vårdrelaterade beslut.

Internetbaserade stödfunktioner såsom patientportaler, webbsidor och vårdrelaterade applikationer av olika slag kan fungera som stödjande funktioner genom att erbjuda information samt underlätta kommunikationen mellan patienter och vårdgivare och möjliggöra patientcentrerad vård. Forskning har visat att dessa former av stöd kan leda till ökat bemyndigande hos patienter som i och med det lättare kan delta i sin vård. Man har också sett att internetbaserad psykologisk behandling har upplevts som användarvänligt och varit till hjälp för personer med cancer som upplever oro och nedstämdhet.

Användning av internetbaserat stöd har visat sig variera beroende på kön, ålder och socioekonomiska faktorer. Man har sett att äldre personer använder internetbaserat stöd mindre än yngre personer vilket bör undersökas vidare för att kunna göra detta slags stöd mer tillgängligt för alla grupper. Personer som diagnosticeras med cancer kan vara i behov av information och andra former av stöd som på ett effektivt sätt kan förmedlas via internet. Det är därför av vikt att undersöka hälsorelaterad internetanvändning i denna grupp samt identifiera hindrande faktorer. Det är också viktigt att utveckla effektiva screeningmetoder för ångest och depression i denna grupp för att identifiera de patienter...
som behöver psykosocialt eller psykologiskt stöd för att kunna erbjuda ett adekvat sådant.

Syfte

Syftet med denna avhandling var att studera hälsorelaterad internet-användning hos personer med cancer samt att utveckla och testa ett generiskt instrument som mäter hälsorelaterad internetanvändning hos personer med hälsorelaterade problem och sjukdom, Health Online Support Questionnaire (HOSQ). Vidare att undersöka och jämföra det korta instrumentet Hospital Anxiety and Depression Scale (HADS) och det ultrakorta instrumentet Visual Analogue Scale (VAS) med de längre instrumenten Montgomery Åsberg Depression Rating Scale-Selfreport (MADRS-S) och Stait Trait Anxiety Inventory-State (STAI-S), med avseende på förmåga att identifiera individer med ångest och depression.

Metod

Studie I var en deskriptiv korrelationsstudie i vilken frågeformuläret Health Online Support Questionnaire (HOSQ) utvecklades och testades. En explorativ faktoranalys gjordes i ett icke-klinisk urval bestående av personer med eller utan hälsoproblem (N=243). Därefter reducerades frågeformuläret från 31 till 18 frågor och validerades i en konfirmatorisk faktoranalys i ett urval bestående av personer med cancer (N=215).

Studie II var en deskriptiv tvärsnittsstudie i vilken hälsorelaterad internetanvändning undersöktes i ett urval av personer med cancer. Frågeformuläret HOSQ administrerades på två öppenvårdskliniker och besvarades av patienter (N=282) som hade avslutat sin behandling, var under monitorering eller hade annan medicinsk behandling. Utöver det besvarades också projektspetsifika frågor.

Studie III var en deskriptiv tvärsnittsstudie i vilken mixad metod användes. Ett ickekliniskt urval (N=231) samt ett kliniskt urval av patienter med cancer (N=208) besvarade frågeformuläret HOSQ samt frågor angående preferenser beträffande psykologisk behandling.

Studie IV var en psykometrisk jämförande studie i vilken det ultrakorta instrumentet VAS och det korta instrumentet HADS jämfördes med de längre instrumenten STAI-S och MADRS-S med avseende på förmåga att identifiera patienter med ångest och depression. Detta gjordes i ett konsekutivt urval av
nydiagnostiserade (<6 mån) patienter med prostata-, colorektal- och bröstcancer, samt patienter med colorektalcancer-recidiv (N=558), som deltog i en internetadministerad interventionsstudie.

Resultat

Studie I. Den explorativa faktoranalysen på den slutgiltiga skalan (18 frågor) resulterade i de två faktorerna ”läsning” och ”Interaktion” och visade på god reliabilitet (Cronbach alphas .88 och .77). Detta bekräftades av den konfirmatoriska faktoranalysen i urvalet av patienter med cancer. Svarsmönstret visade på förväntade skillnader mellan skalorna och demografiska variabler. De som uppgav att de var kvinnor, hade högre utbildning, lägre ålder och ohälsa rapporterade högre användning av hälsorelaterat stöd på internet vilket ansågs styrka validiteten av HOSQ.

Studie II. Totalt 215 (76 %) av deltagarna rapporterade internetanvändning sedan de diagnosticerats med cancer. Internetanvändare var yngre (P < .001), hade mer sannolikt en partner (P = .03) och en högre utbildningsnivå jämfört med de som inte använde internet (P < .001). Den vanligaste hälsorelaterade aktiviteten på internet var att söka information (77 %) och internetanvändarna sökte signifikant mer stöd direkt efter diagnos jämfört med senare (P < .001). Användningen av ”Mina vårdkontakter” rapporterades som den mest värdefulla hälsorelaterade aktiviteten på internet. Universitetsutbildning (P ˂ .001) och lägre ålder (P = .01) var associerat med signifikant högre frekvens av hälsorelaterad internetanvändning.

Studie III. Få deltagare rapporterade internetbaserad psykologisk behandling som preferens i både det icke-kliniska (6,5 %) och kliniska (2,5 %) urvalet. En stor majoritet rapporterade psykologisk behandling face-to-face som preferens. De deltagare som rapporterade mer hälsorelaterad internet-användning för att förbättra sin hälsa eller fatta informerade beslut angående sin behandling föredrog i större utsträckning internetbaserad psykologisk behandling än de som rapporterade mindre användning. Att vara utlandsfödd predicerade preferensen både internet-baserade interventioner och behandling face to face bland patienter med cancer. Rapporterade fördelar med internet-baserade interventioner var flexibilitet angående tid och plats, liten ansträngning, tillgänglighet, anonymitet, trovärdighet, ökat bemyndigande och förbättrad kommunikation mellan klient och terapeut. Rapporterade nackdelar med internetbaserad psykologisk behandling var anonymitet, låg trovärdighet, försämrad kommunikation mellan klient och terapeut och rädsla för negativa biverkningar, krav på datakunnighet samt oro för sekretess.
**Studie IV.** Det ultrakorta och korta internet-administrerade frågeformuläret VAS ångest och depression och HADS visade på en god förmåga att skilja på personer med och utan kliniska nivåer av symptom på ångest och depression jämfört med rekommenderade gränsvärdena på de längre instrumenten MA-DRS-S och STAI-S (AUC: 0.88-0.93). Gränsvärdena 5 och 6 på HADS ångest och 4-8 mm på VAS ångest identifierade patienter med ångest med hög precision. Gränsvärdena 5 och 6 på HADS depression och 4-7 mm på VAS depression visade också på hög precision.

**Slutsats.**

Acknowledgements

My time as a PhD student can be described as an exposure to the endurance of challenges of all kinds. It has made my skin tougher, changed my perspectives and hopefully contributed to the number of connections between my ears. Since I’ve been fortunate enough to have the right people around me it has been a great and enriching exploration.

I sincerely wish to thank all the people who have made this thesis possible, most of all the patients who generously agreed to participate in my studies.

I would like to thank my supervisors. First of all Birgitta Johansson for always being there to answer and discuss my questions and thoughts. I admire your thoroughness, patience and scientific knowledge and have always known that when you say you know something, you truly do.

Erik Olsson, for generously sharing your knowledge on statistical methods and thoroughly reading my manuscripts.

Maria Carlsson, for your sharp eyes for details as well as the bigger picture and for believing in my capacity to solve almost everything by myself, which has taught me to also rely on myself in research.

To both the former and present head of the Department of Public Health and Caring Sciences: Johan Hallqvist, for great support during the shift to my present research group, and Karin Nordin, for your sharp perception and genuine kindness. Thank you for generously welcoming me to the research group *Life-style and rehabilitation in long-term illness*.

Mats G Hansson, my colleague and friend, for all our stimulating discussions about human behaviour, scientific projects (you have many!) and other interesting matters of life. And thank you for being a great support and example of “doing the right thing” at times when it would have been easier not to. You have not only written a book about integrity!

My former roommates Stina Isaksson and Ritva Rissanen, thank you for many stimulating discussions during coffee breaks, lunches and tapas. My former and present colleagues at the Department of Public Health and Caring Sciences: Jennifer Drevin and Jennifer Viberg Johansson, for sharing my passion for the boiling process down to psychology, philosophy and other science. It
is such a joy to discuss thoughts and ideas with you and synthesise. Thank you for continuing the discussions when it feels like everybody else has had enough! ;)

Susanne Hellerstedt Börjesson, for your wise perspective on everything and for silently and verbally keeping me calm. Jenny Thorsell Cederberg, for many stimulating lunches when time was never enough for all our thoughts and ideas.

Marie Kirsebom, for sharing thoughts about life and helping me to prepare for my halftime seminar.

Mio Fredriksson, my childhood friend and mother of my son Jonathan’s two best friends, for letting me know about the PhD position that I applied for and got. I would not have written this thesis if we wouldn’t have had that discussion at the playground six years ago. Thank you!

Martin Cernvall, for not only being a clever researcher but also intelligent enough to be generous and kind to everyone you meet. A talent to be proud of and one that makes the academic world better.

Helena Tegler, Ingrid Demmelmaier and Ylva Tidblad Ehrsson, for constructive feedback on the thesis.

Petronella Bjurling-Sjöberg and Jennifer Viberg Johansson for generously reading and commenting on my thesis during the holidays.

Åsa Andersén, for being there and sharing fresh knowledge on the dissertation process before the D-day.

My present roommates Anna Henriksson and Ann-Sophie Mazzoni, for great company and discussions during coffee breaks and at seminars.

There are so many great memories and persons that it’s impossible to mention all but I’ll do my best: Jenny Stern, Mona Petterson, Maria Grandahl, Maria Gottvall, Marie Höyer Lundh, Annika Terner, Tove Godskesen, Amal Matar, Helena Wandin, Emma Wallin and everyone in the research group Lifestyle and rehabilitation in long-term illness and at the Department of Public Health and Caring Sciences.

I would also like to thank my colleagues at kvinnofridsenheten and NCK. First of all Helen Granered, for taking care of me when I started. I admire your kindness and generosity towards all the people you meet. You are such a role model. Ingela Tegman, for all our discussions about not only work-related matters but also challenges in our own and everybody’s lives. Anna Häger, for handling everything with such an admirable grace. It is a privilege to work next to someone who is so obviously driven by incentives that go way beyond working nine to five. You’ve always had the women in focus (the ones we treat and the ones you hire) despite all the other tasks at your table. Frida von Schantz, for all our interesting conversations about both work-related and personal matters. Aila, Alva, Monica, Pia, Johanna, Madeleine, Elisabeth, Ylva, Annika and all of you. I am so glad to have you as colleagues and to be part of the work against domestic violence.
My dear friend Ana Maria Parra, for being such an access to wider and deeper perspectives. Every single time we meet you give me new perspectives on life. You are one of the smartest and most perceptive persons I know. Thank you for almost 20 years of friendship. Nilla Westöö, we also go way back. Thank you for always listening and being such a great friend. I always manage to sort my thoughts after our discussions. Pernilla Bjerling, for many great memories during trips, dinners, walks and other adventures. I deeply appreciate your scientific perspective on all our discussions about emotional, political and scientific matters. Frida Berglund, I feel so secure when I’m surrounded by wise people like you. We have played the guitar, performed with our own and others songs on solid ground and at sea. You are the only person that I have laughed so much with that my face was aching for a week afterwards!

Frida, Ellenor the dinner club, Katrin, Carina and Cilla and the others, I love our authentic and genuine discussions. There are so many great people in my life and it is impossible to mention you all but you know who you are.

My dear family. My father for teaching me how to maintain integrity and never letting anybody else decide my potential and capacity. My dear brothers, for being such great examples of aiming high and achieving what you aspire to. Jonny, for challenging me in different ways and early on questioning my sources. You are one of the sharpest people I know. Ted, for being such a great and supportive brother. You have always been there and despite all your hard work and success in life you are one of the most generous and humble persons I know. Your families, Ludvig, Noel and Neo, my gorgeous nephews. You are the cutest!

Anders, the best bonus-grandfather in the world! Thank you for always being there for everyone. You have become a dear family member.

My dear mother, for always believing in me and being a great example of strength. You are one of those multifaceted women who are so busy keeping the machine going that it’s hard to realise all the things you do until you don’t. You are a diamond. You have been struggling with poor health during the writing of this thesis, which has given me new perspectives on life. I am so deeply grateful for all your support. You are a great mother and grandmother and it’s bliss to watch you and Leon and Jonathan and your close relationship. I love you.

My godmother Tina, for inspiring me with your intellectual and reflective way of life and for being a great example of emancipation. The childhood memories of you, me and Natasha and our long walks to pick flowers will always stay in my heart.

Isolde and Nathanael, for coming my way. I love taking part of your clever thoughts and reflections. You fill my heart with joy!
Jonas, thank you for always supporting me and for always emphasising the beauty in my nature. I love the way our passionate conversations and discussions never end. I admire you for so many reasons and you stimulate and enrich me in so many ways. Thank you for engaging in my research and helping out when I was finishing this thesis. You are my true companion and partner in crime.

Leon and Jonathan, my beautiful sons and the best sample of them all. You make it impossible to interpret the data without bias. My love for you is the biggest thing I know. Thank you for being so understanding and helpful during the finishing of this thesis! I am so rich to have the opportunity to follow your beautiful natures through life. You are the most interesting, considerate and clever kids I know. No mirror can beat the two of you even though your mirroring is not always that gentle. You make me the luckiest, happiest and strongest person in the world. You challenge me and force me to grow in so many ways. Since the day you were born I have never been bored or questioned the meaning of life. Thank you for being you and for being mine. I love you to the end of the universe.
References


38. SC. UK National Screening Committee. 2011.


Acta Universitatis Upsaliensis

*Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine 1413*

Editor: The Dean of the Faculty of Medicine

A doctoral dissertation from the Faculty of Medicine, 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 Medicine. (Prior to January, 2005, the series was published under the title “Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine”.)