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Web-based counselling to patients with haematological diseases

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Abstract

Patients with haematological diseases are entitled to supportive care. Considering organisational and technological development, support in the form of caring communication provided through the web is today a possible alternative. The aim of this thesis was to examine the usefulness and importance of a web-based counselling service to patients with haematological diseases. The basis for the thesis was a development project funded by the Swedish Cancer Society, which provided an opportunity to offer patients communication with a nurse through a web-based counselling service.

Four studies were performed from a patient perspective. Study I had a cross-sectional design, measuring occurrence of anxiety and depression, and these variables' associations to mastery, social support, and insomnia among patients with haematological diseases. Study II was a qualitative content analysis focusing on conditions for provision and use of the web-based counselling service. Study III used a qualitative hermeneutical approach to focus on patients' experiences of using the counselling service. Study IV was a qualitative deductive analysis examining how communication within the web-based counselling service can be caring in accordance to caring theory.

The results revealed that females of 30-49 years of age are vulnerable to experiencing anxiety. Low sense of mastery and support are associated with anxiety and/or depression. Being able to self-identify the need for support as well as appreciate the written medium are necessary conditions for the web-based counselling service to be used. The counselling service must also be part of a comprehensive range of supportive activities and web-based services to be useful. The main importance of the communication is that the patient's influence on the communication is strengthened, and that the constant access to individual medical and caring assessment can imply a sense of safety. When patients share their innermost concerns and search for support, nursing compassion and competence can substantiate in explicit written responses.

A conclusion is that there is a caring potential in communication within a web-based counselling service. To make this form of communication possible, nurses should take possession of and ensure that this medium for communication is offered to patients. Nurses should also increase their knowledge of caring communication in writing and how this possibly can impact patients.

Original papers

The thesis is based on the following papers, which are referred to by their Roman numerals (I-IV) in the text:

Paper I

Högberg, K, Jutengren, G, Sandman, L, Stockelberg, D, and Broström, A. (2015). Psychosocial factors associated with anxiety and depression in patients with hematological diseases. *In manuscript*.

Paper II

Högberg, K, Sandman, L, Nyström, M, Stockelberg, D and Broström, A. (2013). Prerequisites required for the provision and use of web-based communication for psychosocial support in haematologic care. *European Journal of Oncology Nursing*, 17(5), 596-602.

Paper III

Högberg, K, Sandman, L, Stockelberg, D, Broström, A, and Nyström, M (2015). The meaning of web-based support—from the patients' perspective within a hematological healthcare setting. *Cancer Nursing*, 38(2), 145-154.

Paper IV

Högberg, K, Sandman, L, Broström, A and Nyström, M. Caring through web-based counselling—A nursing intervention. *Submitted to: European Journal of Oncology Nursing*, [2015-02-11].

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Borås 2015,
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I Introduction

To be ill with an acute or chronic haematological disease is serious, no matter whether it comes suddenly or gradually, is acute or chronic, or is life threatening or more easily treatable. Although not all patients consider it as a “crisis”, to experience somewhat disrupted health is anticipated.

The malignant diagnoses are most noted in research as they have a more dramatic significance for the individual than the benign variants of haematological diseases. The medical care of patients with haematological malignancies is becoming increasingly successful; more patients are cured thanks to new therapies (Juliusson, 2014). This means the number of survivors, albeit with various symptoms, increases. This, in turn, raises a need for extended supportive care addressing emotional, social, and physical concerns connected to prolonged survivorship. Nurses have a work-related responsibility and an opportunity to respond to patients’ health problems through communication with patients out of a caring approach. Exhibiting a caring approach means to display a genuine presence and engagement with the individual patient. Such an approach has the potential of promoting wellbeing and alleviating negative senses of illness (Dahlberg and Segesten, 2010). In addition, healthcare offers more structured and directed efforts to promote patients’ psychosocial health. Structured efforts are often accommodated by the concept “psychosocial support”, which includes directed information/education, counselling, or group sessions, also with the objective to promote health.

However, according to research there are insufficiencies in the opportunities for caring communication between patients and nurses within haematological care (Botti et al., 2006; Källerwald, 2007). In addition, unmet support needs are noted among patients with haematological malignancies (Swash et al., 2014). In a Swedish general cancer context, psychosocial support has been considered as insufficient (Socialstyrelsen, 2014b). That there is a need to improve patients’ access to supportive communication is therefore a fundamental starting point for this work.

Another basis for this thesis is the assumption that there is caring potential to patients within communication in a nurse-led web-based counselling service. Such caring is considered to promote health by strengthening patients' ability to master and ease psychological distress (anxiety/depression) and symptoms (insomnia). When plans for this work started in 2006, it was still unusual to provide web-based communication between patients and nurses within Swedish cancer care, and research in this area was sparse. This thesis is therefore based on a development project which in turn was funded by the Swedish Cancer Society.

The project aimed to try a web-based counselling service; meanwhile, four studies were carried out. The aim of the thesis was to examine the usefulness and importance of a web-based counselling service to patients with haematological diseases.

2 Background

This chapter includes background information about the patient group, the healthcare context, and finally the caring potential in communication within a web-based counselling service. Some paragraphs are rounded off with a description of the central concepts of this thesis. The background provides the basis for the rationale described in Chapter 4, which in turn argues for the purpose of the thesis.

2.1 To have a haematological disease

“Haematological diseases” is a collective term for a wide spectrum of diagnoses. Some of the diagnoses are benign, meaning they are kept in check completely with therapy, do not cause major disturbing symptoms, and do not affect the overall lifetime (e.g. some sorts of anaemia or low blood counts due to medications or related to underlying medical conditions). Other diagnoses are more serious as they can cause severe complications or be directly life threatening (Gahrton and Juliusson, 2012). Another way to classify haematological diseases is whether it affects the red cells, the white cells, or the platelets. The blood cells may be malfunctioning or their number too low or too high. Disturbances in the formation of *red* blood cells are associated with anaemia or over-production (e.g. Polycythemia vera). Disturbances in the production or function of the *white* blood cells give rise to what is commonly referred to as blood cancer or haematological malignancies. Disruption in production of *platelets* can cause under- or over-capacity of blood clotting (Hoffman, 2009).

Haematological malignancies include cancer diseases emanating from the cells of the blood-forming organs and the immune system, such as leukaemia, lymphoma, and myeloma. The haematological malignancies are classified into several different diagnoses; some are immediately life threatening and require intensive treatment while others behave more like chronic diseases (Schmaier and Lazarus, 2011). Addressing the incidence of malignant diagnosis in Europe is complicated by the variation of disease classification systems between countries (Sant et al., 2010). In Sweden, however, the inci-

dence of haematological malignancies is relatively stable and approximately 3,400 new cases are detected annually, which means that they represent about 7% of all new cancer cases (Socialstyrelsen, 2014a). Haematological malignancies are, after lung and prostate cancer, the most common cause of death in cancer in Sweden (Juliusson, 2014). The risk of developing a haematological malignancy increases with age, except for some diagnoses which often affect children and young adults (Gahrton and Juliusson, 2012).

Common to haematological malignancies is that the normal bone marrow production is inhibited or disrupted, causing conditions that might produce symptoms in the form of, for example, fatigue, bleeding diathesis, or increased susceptibility to infection (Schmaier and Lazarus, 2011). This is also evident by studies describing the prevalence of symptom burden. Fatigue, insomnia, and pain are highlighted as bothersome symptoms (Johnsen et al., 2009; Manitta et al., 2011). As several diagnoses are life threatening, the uncertainty of the prognosis, cure, and survival can cause distress and problems in adjustment. This is confirmed in qualitative studies describing how the meaning of falling ill with haematological malignancies is perceived as a threat not only to the physical body, but above all against the entire human existence (Källerwald, 2007; Xuereb and Dunlop, 2003). Studies demonstrate that up to 50% of patients with haematological malignancies experience decreased quality of life and symptoms of psychological distress (anxiety/depression) (Clinton-McHarg et al., 2014; Mitchell et al., 2011; Priscilla et al., 2011).

For the purposes of the studies in this thesis, some concepts are focussed on that are descriptive for the health and the ill health of patients with haematological diseases. The most overarching concept is health. Health can be understood as a sense of wellbeing in which the individual is capable of performing life projects (Dahlberg and Segesten, 2010). Health, synonymously used with wellbeing, can be operationalised to be measurable in terms of “quality of life” and is as such a general description of an individual’s wellbeing (or lack thereof) in daily life (Walters, 2009). Health and wellbeing are used as antonyms to illness. According to Dahlberg and Segesten (2010), illness refers to the individuals’ experience of having a disease, and is not equivalent to the display of symptoms. Despite this, in order to relate to previous research and measurability, absence of complete health is focused on

in terms of symptoms in this thesis. Ill health is therefore used ahead as an overall term for the exhibition of any negative physical/psychological/social symptoms. In light of the above referenced studies, insomnia seems to be a potentially relevant problem for patients with haematological diseases. Insomnia is a sleeping disorder wherein there is a failure to either fall asleep or stay asleep as long as wanted (Harvey, 2001). Psychological distress is used as a generic term for anxiety and depression, and is also stated as a relevant concern for patients with haematological diseases. Anxiety is about concerns ranging from nervousness to fear or full-scale panic (Passer, 2009). Depression refers to a mood that is sad, with dulled affect, as well as apathy and lack of energy (Passer, 2009). Psychological distress and anxiety/depression are used interchangeably and basically synonymously in the thesis.

No studies have been found focussing on quality of life and the symptoms insomnia, anxiety, and depression among patients with haematological diseases in a Swedish context. In spite of no actual prevalence rate, an assumption of illness, here described in terms of disrupted quality of life and increased levels of symptoms, among this patient group is the prime reason why this project was carried out. Patients' signs of ill health can be understood as there being a need for support, which motivates the implemented web-based counselling service. The main objective with the communication within the counselling service was to promote health, i.e. quality of life and reveal ill health, i.e. symptoms like insomnia, anxiety, and depression.

2.2 To handle having a haematological disease

Understanding how patients react to and handle having a haematological disease is important, as this is part of the knowledge necessary to encountering patients in a caring way. Dahlberg and Segesten (2010) describe how “to handle” illness in terms of patients' reformulating their life situation to respond creatively to the disease. A more tangible and common way to understand and explore how patients handle their illness is to rely on theories of coping. Theories of coping strategies can also be understood as the starting point for design of structured psychosocial supportive efforts provided by healthcare.

How patients handle their haematological disease varies, according to empirical research. The strategy “obtaining control” is one of the most frequently used strategies for patients with haematological malignancies. Actively coping and searching for information in order to try to understand are highlighted as ways to manage the situation of having a haematological malignancy (Koenigsmann et al., 2006; Priscilla et al., 2011; Xuereb and Dunlop, 2003). In addition to obtaining control, increasing hopefulness is another common strategy, according to a systematic review by Koehler et al. (2009). This can be achieved by avoiding or denying information (Hoff et al., 2007; Priscilla et al., 2011). Other strategies are venting or the use of emotional support (Koehler et al., 2009; Priscilla et al., 2011). Farsi et al. (2010) reveal that patients with haematological diseases tend not to make use of one single and consistent way to relate; rather there is a dynamic in the management processes. In other words, how a patient reacts and handles having a severe diagnosis is not a static state.

One way to theoretically understand how patients with haematological diseases handle their illness situation is to consider Lazarus and Folkman’s psychological theory of stress, appraisal, and coping (Lazarus and Folkman, 1984). The main features of the theory are that appraisal of a stressful situation is an evaluation process consisting of the interplay between personalities and environmental circumstances, which determines the emotions that arise. Based on the above review of strategies, it appears that an environmental or external support in the form of informative and emotional supportive communication (i.e. the implemented counselling service) might be able to facilitate patients’ handling of their situations.

One way to understand external support is to see it as strengthening the individual’s own inner resources. Pearlin and Schooler (1978) describe the individual’s inner resources in terms of “Psychological resources”, which, in turn, stand for the personality characteristics: self-esteem, self-denigration, and mastery. In this thesis, the concept of mastery is of interest. The sense of mastery is defined as the extent to which one believes life changes are under one’s control or if they are fatalistically ruled (Pearlin and Schooler, 1978). Mastery was originally considered a rather constant trait, yet Pudrovska (2010) state that while being infected by a severe disorder, the surrounding circumstances make the future somewhat unpredictable, no

matter the inner sense of mastery. Mastery can therefore be understood as a changeable state when in a difficult disease situation.

Mastery is considered as responsive to supportive efforts, and was in this thesis chosen to represent what the focused web-based counselling service intends to strengthen. That is, by having access to a caring communication through a web-based counselling service, the patient's sense of mastering a situation is believed to be reinforced.

2.3 Caring for patients in a haematology context

As signs of ill health as well as ways to handle a disease situation vary; likewise, patients' needs for support differ. In a clinical haematology context, a distinction is usually made between medical treatment and structured psychosocial support. Nursing care is typically offered during medical treatment and the nurse normally has the role of mediating the contact with more directed psychosocial support resources. The following sections describe these two care structures and the nurse's supporting role within the respective structures.

2.3.1 *Medical and nursing care*

The prognosis for haematological diseases varies by diagnosis, age, and treatment. The treatments of the different malignant diagnoses are chemotherapy, radiation, and, in some cases, stem cell transplantation. Chemotherapy is used in order to kill cancer cells and is typically administered as scheduled treatments except for more indolent chronic diagnoses, where the medication instead can consist of a low continuous dose. Radiation is used to destroy diseased cells in a more localised area. Stem-cell transplantation may be required in severe cases, preceded by a very powerful treatment of chemotherapy/radiation that damages the patient's own production of blood cells (marrow or stem cells). The deleted haematopoiesis is then replaced with new, healthy cells, which can be either the patient's own collected and purified cells, or new from a donor (Schmaier and Lazarus, 2011). The non-malignant haematological diseases are a heterogeneous collection of diagno-

ses, which often requires frequent treatment, monitoring, and blood sampling. Some diagnoses have the potential to transition to being malignant over time. The treatment of these diagnoses is normally characterised by the addition of red blood cells or platelets, if there is a deficiency condition being treated. Alternatively is normalising blood values by exsanguination, if the problem is over-production. Furthermore, the cause behind the current disease must be treated by medication (Gahrton and Juliusson, 2012).

In itself, the medical treatment of haematological malignant diseases is described as physically diminishing and a drain on energy from a patient perspective. The physical “decay” in terms of weight loss and fatigue will be a reminder of the severity of the disease (Källerwald, 2007; Persson and Hallberg, 2004). To become decrepit by illness and treatment also means changes in relation to the environment. This may bring new perspectives on life and meaning, and new relationships in the form of dependence on others (Farsi et al., 2010; McGrath, 2004).

The division of labour in the medical treatment of patients with haematological diseases is traditional, meaning that physicians prescribe and nurses normally perform the main distribution of treatment. This involves physical inspections and blood sampling, and administration of intravenous medications, but also the coordination of different health care interventions and care planning (Onkologiskt centrum, 2004). This, in turn, means nurses have considerable contact with patients and thus occasions to carry out communication. Empirical research on the nurse perspective demonstrates that the meaning of caring for patients (with different cancer diagnosis) is characterised by getting involved in a mutual closeness, in turn demanding compassionate presence and listening (Iranmanesh et al., 2009). According to a study by Quinn (2003) on nurses supporting cancer patients in their search for meaning, some aspects appeared particularly important: spending time, having the ability to communicate, and having the courage to be with patients in their suffering were conditions for being able to truly care for patients.

From a theoretical perspective, caring communication gives patients an opportunity to disclose how they feel. Space for such a narrative, in combination with a dignified reception, has the potential to alleviate negative feelings

(Fredriksson and Eriksson, 2003). This can occur if the nurse is unprejudiced, open, and compliant to the individual patient. Communicating in a caring way has its origins in the nurse's having a caring approach. This means that by upholding a caring approach and striving to communicate in a caring way, the nurse has an ability to promote wellbeing and alleviate experiences of illness (Dahlberg and Segesten, 2010). To uphold a caring approach reflecting a genuine presence and engagement is referred to as a central part of nursing care by several caring or nursing theorists (Dahlberg and Segesten, 2010; Watson, 1988). This is also included in the recommendation of nurses' skills and attitudes (Socialstyrelsen, 2005).

Research on a patient perspective on these aspects of caring argues that patients wish to communicate existential issues with nurses, but such talks are sometimes difficult to achieve due to absence of time and courage among personnel (Källérwald, 2007). Comparable results are presented by Berg and Danielson (2007), revealing that nurses lack the time and courage to provide care, where patients (with different diseases) can experience authentic trust and share their innermost feelings. However, Kvåle (2007) has shown that patients with cancer do not always want to talk with the nurses about their difficult feelings because they preferred cognitive avoidance and distancing by, instead, talking about normal life, hobbies, or their families. Or they preferred support from family and friends rather than professionals.

2.3.2 Psychosocial support

Intertwined with providing medical treatment, nurses have an opportunity to conduct communication with the potential of being caring. More targeted and structured efforts, albeit with a quite similar purpose and goal, are the activities contained in the overarching concept of psychosocial support. Psychosocial support is well established in wider cancer care and refers to structured efforts addressing psychological and social problems associated with the illness (Adler and Page, 2008; Carlsson, 2007). In a Swedish context, the term often comprises multiple professional roles (social worker, psychologist, physiotherapist, occupational therapist, and dietician) and is thus more of a collective term for all actions performed by the consulting staff than support of only patients' psychosocial wellbeing (Vårdguiden, 2013). Another perhaps more correct term for efforts by all these corresponding

professions is cancer rehabilitation (Regionalt Cancercentrum Syd, 2014). The nurse is mainly described as a link between various health care providers and the one who knows where to turn to for support when an elevated need for support occurs (Vårdguiden, 2013).

From a theoretical perspective, “psychosocial support” can be seen as professional assistance to the patient in the struggle to adapt to and master the new situation of having an illness. How psychosocial support is related to health can be explained by its either mitigating the stress appraisal or alleviating the emotions that arise (Cohen et al., 2000). Psychosocial support activities in cancer care can be categorised as informational, emotional, social, or instrumental support (Adler and Page, 2008). The purpose of all these activities is to improve the patient’s wellbeing in different ways; information can contribute to a sense of control or mastery; emotional support means alleviating and confirmation of emotions through talks; social companionship with others can mean the normalisation and confirmation of one’s situation; instrumental support includes practical assistance (Ibid.).

According to guidelines in cancer care, the demand for psychosocial support is indisputable (Socialstyrelsen, 2014b). But Swash et al. (2014) declare in a review of studies with mixed cancer populations (all including haematological diagnosis) that there are problems in terms of unmet needs of support. Lack of information, fear of recurrence, and problems with fatigue and anxiety were the most common unmet needs. Deficiencies in the care of patients with haematological diseases is noted also by Molassiotis et al. (2011); the most important need is help with practical assistance and worries about relapse and stress in general. Help to manage concerns about the cancer’s coming back is also ranked as the most urgent need among patients with haematological malignancies in a study by Lobb et al. (2009). Almost two thirds of the patients reported that they would have found it helpful to talk with a health care professional about their experience of the disease at the completion of treatment (Ibid.).

The nursing role and the nurse’s traditional ability to meet the patient’s need for supportive care through caring communication and by upholding a caring approach is a basic assumption in this thesis. By implementing a directed and structured channel for web-based communication between patients and a

nurse, here called counselling, this can also be understood as a strengthening of the range of directed psychosocial support efforts.

2.4 Nurse-led web-based counselling

Within this research project a possibility for patients to communicate with a nurse through a web-based medium was introduced. As the communication method needed a location in the healthcare services, a positioning in relation to the existing structures, as well as a title, the appellation “counselling” was chosen. This was not the first choice: in study II it is referred to as “psychosocial support”; in study III “web-based communication for support”. These changes have to do with progression of understanding during the project.

Nurse-led counselling is a structured supportive activity that aims to provide patients with information and emotional support. The intention of counselling is to let patients explore and apply words to their own situation that normally is a negative state of mind about something. The corresponding guidance can consist of information or emotional confirmatory response (Towers and Diffley, 2011). In the current web-based counselling, the medium for communication is text and the interaction process is asynchronous, which means a time delay between the messages. In the field of psychology this is referred to as “online counselling” and experiences and recommendations for practice has been well documented for several years (Zack et al., 2004). Within cancer care, however, this has not been regularly used. Schnur and Montgomery (2012) demonstrate that only five out of 120 cancer caregivers (in the United States) conducted online counselling.

There is no clear consensus on the use of terminologies in the research on nurse-led communication or the provision of information and emotional support (roughly what has just been defined as counselling) that are web-based. Such a possibility was, until recently, mainly studied as part of multifunctional psychosocial support systems that, in addition to nurse-led communication, include several functions: information/educational material, forums, and group sessions. In such contexts, communication with a professional is not consequently referred to as counselling but rather “communication with an expert”, “ask-the-nurse service,” or simply, “e-mail function”. Within such a multifunctional system to patients with breast and prostate

cancer (WebChoice), the e-mail function has been shown to be the most used and valued function (Ruland et al., 2013).

A study on experiences and use of exclusively online communication between patients with testicular cancer and a nurse shows that such a service can mean a way to ensure information flow and manage illness-related concerns from home (Wibe, Hellesø, et al., 2012). Another study, focussing on the content in e-mails between patients with lung cancer and a nurse, demonstrate that the communication contained administrative or medical queries, or self-expressions of what was happening in life (Cornwall et al., 2008). Related findings are reported from Grimsbø et al. (2012) analysis of online communication for patients with breast and prostate cancer; the communication contains concerns about physical symptoms, unpleasant emotions, and questions and concerns about the future.

When it comes to importance in terms of effects on health variables of web-based counselling, research is still sparse. David et al. (2011) evaluated breast cancer patients receiving online counselling from a psychologist and revealed a high degree of satisfaction in the intervention group, but no significant improvements in distress or quality of life. The lack of significant effects was explained by the service's relative weaknesses; a two-month session was reflected as too short and the exchange of e-mails was too infrequent. It was also unknown as to what extent advice was accepted by patients (Ibid.). In an evaluation of the effects of e-mail communication in comparison to usual care and a multifunctional system (WebChoice), the e-mail function had positive effects on depression, but the multifunctional system had effects also on distress and anxiety (Børøsund et al., 2014).

2.4.1 Request for and barriers to provision of web-based counselling

As mentioned in the introduction, web-based communication between patients and their caregivers was not regularly used in healthcare, thus the starting point for the project behind this thesis. This lack endures despite the need for alternative solutions for communication that has become more urgent by changes in the healthcare organisation (Huston, 2013). When healthcare is increasingly moving from inpatient to outpatient care, there are

fewer opportunities for patients to obtain information and emotional support through face-to-face encounters and oral conversation (Ibid.). This has been well known for decades, and use of information and communication technology has been requested for almost as long a time (Regeringen, 1995; Socialdepartementet, 2010).

There has been great anticipation that the introduction of various web-based solutions will improve the quality of care in terms of increased availability and security. However, the introduction has been slow; in 2005 this was explained by systems' being originally used for separated activities without any coordination; the cost of an all-embracing IT system's being considered too high; and the need for communication's not fully being perceived (Socialdepartementet, 2005). More recent research highlights human obstacles such as hierarchical structures, professional pride, and threats to professional identity as causes of the continuing inertia in Swedish healthcare's adaption of IT solutions (Nilsson, 2014). An additional obstacle for providing web-based counselling seems to be lack of knowledge among healthcare personnel (Schnur and Montgomery, 2012).

3 Theoretical framework

This thesis is based on the patient perspective. This means that the patient's experience of health is in focus for care as well as research. A patient perspective can include family members as they often are crucial to the patient's ability to experience wellbeing (Dahlberg and Segesten, 2010).

Some guiding concepts for the thesis have been presented in the background. These are health and caring in terms of how they are expressed in communication and by the nurse's approach. The definitions are based on Dahlberg and Segesten's (2010) descriptive theory on health and caring that is developed nearby geographically, culturally, and in time. Additionally, more internationally recognised and referenced theories have, on an abstract level, broadly similar content. Therefore, I would argue that this essence is neither unique nor new, but rather acknowledged and conventional in terms of the perception of caring. For example, relation and communication are well and truly emphasised as central to caring in nursing interaction theories such as "Interpersonal Relations" by Peplau (1952). In Peplau's theory, the focus is on how the interpersonal process between patient and nurse enables a good care. A stable relationship and good interaction are achieved through the phases in the evolution of the relationship between patient and nurse, and together this is believed to support the patient in the process towards health. Likewise, exhibiting a caring approach is central to internationally acknowledged major nursing theories like Watson (1988) "Theory of Human Caring". According to Watson, a caring approach includes exhibiting warmth, genuine interest, and empathy in order to promote health and alleviate suffering (Ibid.) Watson's adherent, Swanson, also describes the nurse's caring, but in a middle-range theory and thus slightly less abstract. The theory of Caring by Swanson (1991) is composed of five categories describing subdivisions of caring: knowing, being with, doing for, enabling, and maintaining trust. As Swanson's theory is, to some extent, categorising, it was deductively used as a matrix in the analysis in study IV.

As the implemented web-based option for communication required a title and a structured affiliation to give it context, the concept counselling was

finally chosen. To introduce a communication tool with the title “caring communication” was not considered as an alternative as this was seen as too vague. As psychosocial support covers structured supportive efforts, the counselling service was determined to belong to this particular structure of healthcare. In addition, the ambition to assess effects demanded a description of the health-promoting mechanism in measurable terms. To measure effects in terms of promoted health and alleviated senses of illness was not suitable. The concepts informational and emotional support, mastery, quality of life, as well as symptoms like insomnia, anxiety, and depression were therefore chosen. These concepts are carefully operationalised to be measurable and thus useful in this thesis, as well as frequently used in also other nursing research.

4 Rationale

Patients with haematological diseases experience illness in varying degrees; to what extent this occurs in the Swedish population of patients with haematological diseases is not fully clear. Nevertheless, this patient group is entitled to supportive care. The nurse's communication with patients carries a potential for caring where patients receive an opportunity to debrief about their disrupted wellbeing and obtain an empathic reception. This can function as caring, i.e. to alleviate experiences of illness. In addition, structured psychosocial support efforts such as providing information and emotional support are common supportive strategies. These strategies intend to strengthen patients' sense of mastery and ease psychological distress and other symptoms. However, we know that insufficiencies in the provision of caring communication as well as structured support efforts have been noted in research on care to patients with haematological diseases. There is a need for knowledge on how these deficiencies can be remedied.

Structural development in healthcare organisations such as more outpatient care causes fewer opportunities for personal meetings and communication between patients and nurses. In combination with more easily accessible Internet and further technical development, new methods for care become both possible and desired. There are reasons to expect that a web-based counselling service can be one way to enable caring communication between patients and a nurse, but we lack knowledge in terms of what is necessary for such a service to work. To make it clear on what basis we should offer such a form of communication, this also needs to be further defined from a patient perspective. Several questions must be addressed: for whom is a web-based counselling service appropriate? When and to what purposes is it used? What can it possibly mean from a patient perspective? How can it affect patients' wellbeing? How can web-based communication be caring? Answers to these questions are important to understand if and how patients' needs for support can be met through web-based communication.

Some of these questions can be included into the concept usefulness, which not is an inherent quality but refers to the extent to which the web-based

counselling service can be used by specific users to achieve specific goals within a specific context. Other questions can be grouped under the term importance, which refers to what the counselling service can possibly mean, cause, or lead to. Altogether, knowledge about the usefulness and importance of web-based counselling between patients with haematological diseases and a nurse was considered to be insufficient. By introducing an opportunity for web-based counselling on a haematology clinic, it was possible to study different aspects of the phenomenon from the patient perspective.

5 Aim

The comprehensive aim of this thesis was to examine the usefulness and importance of a web-based counselling service to patients with haematological diseases.

The specific aims of the studies included were:

- I. To describe the occurrence of anxiety and depression as reported by the patients, as well as to investigate the associations with physical health status, insomnia, mastery, and informational/emotional support within patients with haematological diseases.
- II. To describe the prerequisites required for the provision and use of web-based communication for psychosocial support¹ from a patient and family² perspective.
- III. To describe the meaning of using web-based communication for support from a patient perspective.
- IV. To examine how communication can be caring between patients with haematological diseases and a nurse within a web-based counselling service.

¹ There has been some concept development during the project; the counselling service referred to in the studies refers to the same counselling service, albeit with different names.

² Family members were considered to participate also in the subsequent studies, but given that they were difficult to recruit, this group was excluded in the remaining studies.

6 Method

This section is intended to first describe the settings, the process of the project together with the intervention/the web-based counselling service, the design of the studies, the participants, and a schedule of the studies. This is followed by more thorough descriptions of data collection and analysis for each of the studies I-IV. A few lines describing how the synthesised analysis was conducted to answer the questions in the rationale precede the ethical considerations that round off this section.

6.1 Settings

The haematology clinic where this research project took place consists of an outpatient facility and an inpatient ward. Patients with suspected diagnosis are referred to the clinic for thorough investigation. After diagnosis, patients are linked to a team. Patients are then followed by their team for further treatment and checks. As far as possible, the medical treatment is given on an outpatient basis, but for longer treatments or in case of special needs, care is conducted in the ward.

The outpatient work is organised into diagnostic teams; a small number of physicians and nurses work continuously together with patients with the same or similar diagnosis. Patients are divided into:

- ✓ Lymphoma team (treating patients with Non-Hodgkin's lymphoma, CLL/chronic lymphocytic leukaemia, B- or T- cell lymphoma, Hodgkin's lymphoma).
- ✓ Anaemia-/Leukaemia team (AML/acute myeloid leukaemia, ALL/acute lymphoblastic leukaemia, MDS/myelodysplasia syndrome and various anaemias, PNH/ paroxysmal nocturnal haemoglobinuria, Thalassaemia, Sickle cell disease and other congenital or acquired anaemias).
- ✓ Plasma cells team (Myeloma, plasmocytoma, MGUS, Amyloidosis)
- ✓ Myeloproliferative diseases team (PV/polycythaemia vera, ET/essential thrombocythaemia, MF/myelofibrosis, CML/chronic

myeloid leukaemia, ITP/immune thrombocytopenia, HKR/ haemochromatosis).

As the clinic performs bone marrow or stem cell transplantations as well, there is also one team that works with the investigation, information, and implementation of blood stem cell collections of both patients and donors.

Accommodations with multiple beds are connected to each team for the patients attending the clinic as outpatients. Several patients are processed simultaneously by the team staff during on weekdays. The inpatient ward receives patients in need of hospitalisation because of sickness or rigorous treatment. At such visits patients are assigned to a responsible nurse for that specific occasion of care.

Structured psychosocial support resources are also linked to the clinic. These are of “traditional character”, mainly meaning that a social worker is available for emotional counselling and social/financial advice. In addition, there is a central hospital chapel and information is also given on non-profit support organisations’ resources such as Blodcancerförbundet (The Blood Cancer Association). Brochures and message boards are available at the clinic to spread information on psychosocial resources. Patients or family members are encouraged to contact these resources themselves, or request help from a nurse on the clinic. At the time of the project’s genesis, web-based communication between patients and healthcare staff was not available.

6.2 The project process

The planning of the research project started in conjunction with the haematological clinic in 2006. Web-based communication between patients and healthcare staff was very much expected as a result of political ambitions. For that reason, it was desired for the service to be as simple as possible to make it sustainable in the long run, i.e. to persist even after completion of the research project.

A system called Mina Vårdkontakter (“My Care Contacts”) was used. At the time point for this project, there was a decision in the region to make use of this particular system for communication, but it was not yet implemented.

Because of this project, the implementation was under time pressure and hastened. We introduced a case type labelled “Psychosocial support”. This channel for support was defined as to include information, advice, and guidance for conditions where individuals perceived themselves to be in need of support. Participants needed to log in by use of an e-card or special login and password; then select the case type “Psychosocial support”; and then write down their issue and submit it. Family members could access the system through the enrolled patients’ ID numbers. This implied that the patient authorised this use. There was information that the responding nurse had the responsibility of monitoring the incoming cases and sending a reply within three days. To avoid the need to monitor whether a response had arrived, the user could choose to receive a reminder via a mobile phone text message or email. The nurse belonged to the regular staff and had access to all the patients’ medical charts.

6.3 Design of the studies I-IV

All four studies had different study designs; all, however, were performed out of a patient perspective. Family members were included in one study. An overview of the four studies is presented in Table 1.

Study I had a quantitative cross-sectional design assessing occurrences and associations among a selection of variables in a sample of patients with haematological diseases at one time point. With such a quantitative model, regular associations among variables are searched for in order to be able to describe a phenomenon (Kazdin, 2003).

Study II was an inductive qualitative content analysis based on Graneheim and Lundman (2004) focussing on interviews of patients with haematological diseases as well as family members’ experiences of having access to the web-based counselling service. Hsieh and Shannon (2005) describe content analysis as a method that has no explicit epistemological foundation, i.e. there is no underlying theory that explains what knowledge is or how it is created. The analysis of text data is done by a systematic classification process of coding and identifying themes or patterns. Graneheim and Lundman (2004) describe a conceptual framework for how the different steps of the analysis can be performed and labelled.

The original project idea was to evaluate the service via a randomised clinical trial (RCT), hence the interest in variables that represent what the service was intended to affect, as well as recruitment of participants to a study with a two-group experimental design. Given that the RCT study was finally deemed too weak, study III and IV within the thesis were mainly focused on qualitative data collected as part of the RCT design.

Study III used a hermeneutical lifeworld research approach (Dahlberg et al., 2007) to conduct interviews with patients with haematological diseases. The approach is based upon the philosophy of hermeneutics as an art of interpretation and understanding, as suggested by (Gadamer, 1994). According to Gadamer (1994), a phenomenon can be understood in several ways as we are always inevitably influenced by our past experiences. Consequently, Dahlberg et al. (2007) state that as researchers always have pre-understandings despite striving for objectivity, a successful analysis is the result of creativity and the ability to go beyond what is familiar and obvious, yet without losing the requirement of reasonableness and meaningfulness.

Study IV was based on a qualitative and deductive content analysis in accordance with Elo and Kyngäs (2008). A deductive analysis is a structured process using existing theory (Hsieh and Shannon, 2005). This meant that text-based communication produced within the counselling service was analysed out of a theoretically predetermined matrix based on Swanson's Theory of Caring (Swanson, 1991).

6.4 Participants

In study I, a convenience sample of 120 patients was recruited by the nurse during 2012-2014. Inclusion criteria included having a haematological disease, being at least 18 years of age, and communicating in the Swedish language. Out of the 120 patients, 50% were female, the mean age was 55.9 years of age, and 67% had a malignant diagnosis. 39% were receiving treatment in order to cure the disease, 55% received chronic maintenance treatment, and 6% received palliative care.

In study II, a convenience sample of 11 patients and 6 family members were included and given access to the web-based counselling service for communication with a nurse. Inclusion criteria were being diagnosed with a haematological disease or being a family member to one diagnosed, being over 15³ years of age, and mastering the Swedish language. The sample was strategically selected (Patton, 1990) in order to achieve variation in the characteristics of age, gender, and diagnosis. Nine were female and eight were male, the mean age was 44.8, the age range 22-68, and all patients had a malignant diagnosis.

Participants in study III and IV were originally recruited to a comprehensive study with an RCT design. Of the requested 56 patients, 30 agreed to participate, and these patients were randomised to either an intervention (N=15) or a control group (N=15). The control group received treatment as usual, i.e. no web-based counselling. The intervention group was given access to the web-based counselling service. Inclusion criteria for participation were being diagnosed with a haematological disease, being over 18 years of age, mastering the Swedish language, and not receiving other psychosocial treatment other than standard care at the clinic. Two participants dropped out and one deceased in the intervention group. Two were considered too ill to participate in interview study III; therefore, 10 of 15 were requested to and consented to participate in the qualitative study III. Six were females and four were men, the mean age was 51.5, and the ages ranged between 21-72 years.

In study IV, the written messages produced by participants in the experimental group and the responding nurse were in focus for the analysis. As two patients dropped out and one deceased, 12 participants' data was left accessible for analysis. Two did not write any messages and thus generated no data for this particular study. The remaining 10 patients and the responding nurse were the remaining participants in this study. Six patients were women and four were men, the mean age was 48.9, and the ages ranged between 21-72 years.

³ In study II, being over 15 years of age was an inclusion criterion because this is the limit according to legal ethical guidelines in Sweden. At the clinic, however, only patients over 18 years are cared for; therefore 18 years became the more natural limit for inclusion in the other studies.

Table 1. Overview of the studies I-IV, design, aim, participants, methods, and time points for data collection and analysis.

Study	I	II	III	IV
Design	Quantitative cross-sectional	Qualitative content analysis	Qualitative hermeneutical	Qualitative deductive content analysis
Aim	To describe the occurrence of anxiety/depression and the associations between the assessed variables	To describe the prerequisites required for the provision and use of web-based communication	To describe the meaning of using web-based communication for support	To examine how web-based communication can be caring
Sample of participants	Convenience sample N=120 patients	Convenience sample N=17 11 patients 6 family members	Randomised participants in the experimental group N=10 patients	Randomised participants in the experimental group N=11, whereof 10 patients, 1 nurse
Data collection	Questionnaires 2012-2014	Interviews 2012	Interviews 2013	54 written messages from patients, 55 from nurse 2013
Data analysis	Group comparison Correlations Logistic Regression 2014	Qualitative content analysis 2012	Hermeneutical analysis 2013	Deductive qualitative content analysis 2014

6.5 Data collection and data analysis of the studies I-IV

6.5.1 Study I

Data collection

Patient and disease characteristics

Data regarding age, gender, marital status, and education level were collected from patients. Information on diagnosis, time since diagnosis (in months) and treatment status aim (cure, chronic maintenance, or palliative) were collected from medical charts by the project nurse.

Anxiety and depression

The Hospital Anxiety and Depression Scale (HADS) is a 14-item self-reported scale that assesses anxiety and depression with seven items with four response alternatives (0-3), respectively. This yields a total score for anxiety or depression ranging between 0 and 21, with higher scores indicating higher symptom levels. For each sub-scale, a score of 7 or below is regarded as the normal range and 8-10 indicates a risk of disorder; above 11 indicates a probable presence of a mood disorder (Snaith and Zigmond, 1986). HADS has been used in studies among cancer patients in Sweden and been found to be reliable (Saboonchi et al., 2013).

Quality of life/Physical health status

The Short-Form Health Survey (SF-12) is a generic and abbreviated alternative to the 36-item health status questionnaire SF-36. SF-12 produces two summary scores: a physical component (PCS) and a mental component (MCS⁴). In this study, we focussed on the PCS wherein 6 items summarise physical functioning, role limitations due to physical problems, bodily pain, and general health. The role-functioning scales have dichotomous response alternatives: yes or no. The other items have three to six response choices. The 12 items are scored and transformed according to the standard procedure in the manual; a higher score reflects better self-rated health (Ware et al., 1996).

⁴ The MCS summarises vitality, social functioning, role limitations due to emotional problems and mental health.

Insomnia

The Minimal Insomnia Symptoms Scale (MISS) consists of three items collecting the central symptoms of insomnia, i.e. difficulty initiating sleep or maintaining sleep and non-restorative sleep. Each item has five response choices: no problem (0), minor problems (1), moderate problems (2), severe problems (3) and very severe problems (4). Total score ranges from 0 and 12, wherein higher scores indicate more severe insomnia. A cut-off score of ≥ 6 is suggested to characterise subjects with clinical insomnia (Broman et al., 2008). MISS has been found to be psychometrically sound in general and elderly populations in Sweden (Hellström et al., 2010).

Mastery

The Pearlin Mastery Scale is made up of seven items consisting of statements addressing the sense of control over what happens in life, as opposed to one's life being controlled by outside forces. The respondent rates how strongly he or she disagrees with those statements (1-strongly agree to 4-strongly disagree). Total score ranges from 7 to 28, wherein 28 indicates the highest degree of mastery (Pearlin and Schooler, 1978). The Swedish version of the scale has been psychometrically tested and shown acceptable reliability and validity (Eklund et al., 2012).

Social support/Informational and emotional support

The Medical Outcomes Study—Social Support Survey (MOS-SSS) is a multidimensional questionnaire with four scales (19 items in total) covering different aspects of social support (informational and emotional support, positive social interaction, affection and tangible support). In this study, we were interested in the first subscale assessing informational and emotional support with eight items. For all items, five answer options were available: “none of the time,” “a little of the time,” “some of the time,” “most of the time,” and “all of the time” (Sherbourne and Stewart, 1991). The score for each scale is calculated as a percentage of the maximum score possible in that dimension. Results thus range from 0 to 100, with higher percentages indicating higher levels of perceived support. MOS-SSS has been used in Swedish contexts and has demonstrated satisfactory reliability (Baigi et al., 2008).

Data analysis

Data were analysed using Statistical Packages for Social Science (SPSS) 21 for Windows. Correlations between independent self-estimated outcome variables were calculated by Spearman (Rho). To explore the associations among anxiety, depression, physical health status, insomnia, mastery, and emotional/informational support, logistic regression analyses using the Enter method (meaning all independent variables were inserted in the model in one step) were performed. The Nagelkerke R² as a summary measure of the dependent variables was used. The Nagelkerke R² is developed for logistic regression, but made to resemble the ordinary R². Generally, higher values indicate stronger association between the variables, but it cannot be interpreted as the proportion of explained variance (Bjerling and Olsson, 2010). The Hosmer and Lemeshow test was used to provide an overall measure of each model's explanatory power. Values exceeding .05 indicate that the models give values which do not differ more than what could be explained by random chance. That a model is significant does not, however, mean that it necessarily explains much of the variance in our dependent variable, only that it is significant (Bjerling and Olsson, 2010). The unique contribution of each independent variable was assessed by odds ratio (OR).

6.5.2 Study II

Data collection

Data were collected through open interviews with patients and family members about four months after recruitment. Fourteen interviews took place in a quiet location at the clinic and three were conducted in the participants' homes. All interviews lasted for ½ to 1½ hours, were audio recorded, and transcribed verbatim. The interviews started openly by asking the participants to talk about their experiences of having access to the web-based counselling service related to their illness or their family member's illness. Follow-up questions aimed to direct the participants to the studied phenomenon in accordance to Kvale (1996). The interviews included questions regarding what prevented or allowed the use of web-based communication for support.

Data analysis

The analysis process was based on Graneheim and Lundman (2004), meaning the transcribed interviews were initially read to gain a sense of the

whole. The text was then separated into meaning units, where a meaning unit is a constellation of words that relate to the same meaning. The next step was to condense while still preserving the core of the content. These condensed units were interpreted (in the sense of abstracted) and organised into groups with similar meaning and labelled with a code. The codes were compared and sorted according to differences and similarities, and summarised into subthemes, which in turn were abstracted into themes.

6.5.3 Study III

Data collection

Data were collected through open and pliable research interviews (lasting for 1 to 1½ hours) with patients (Dahlberg et al., 2007). The interviews were held at about 3 months after they had been given access to the counselling service. All interviews took place at the clinic, were audio recorded, and transcribed verbatim. An initial open-ended question was used: “Can you please tell me about your experiences of using the web-based communication for support?”. The patients were then directed to reflect on the phenomenon by open questions such as “What was it like?”.

Data analysis

The analysis was based on Gadamer’s approach to hermeneutics (Gadamer, 1994). His theory of understanding has been developed into an empirical analysis tool for qualitative data by Dahlberg et al. (2007). The analysis was seen as phases in a dialectic process of moving between the whole text and the parts. The analysis process was focussed on the meanings in the text by asking innovative questions in attempts to be open to what was shown in the text and not only what was in accordance with preconceptions (Dahlberg et al., 2007). This meant having an examining dialogue with the text, where suggested interpretations were tested against empirical data. Most of the interpretations were rejected because they did not endure in comparison with the data. The final step was to compare the remaining interpretations and search for a deeper meaning to arrive at a more abstract interpreted whole.

6.5.4 Study IV

Data collection

Content comprising two months' use of the web-based communication, i.e. 54 messages from patients and 55 responses from the nurse, were gathered and constituted the data material in this study.

Due to the comprehensive RCT study design, several variables were available describing the participants. These descriptive data together with each participant's frequency of communication (the number of messages and length in average number of words per message) were therefore included in the description of the participants.

The descriptive variables were age, gender, marital status, and education level (primary, secondary, university), collected from patients. Diagnosis, duration of disease (months since diagnosis), purpose of treatment (curative treatment, chronic maintenance treatment, palliative treatment) were collected from medical charts. Variables from the questionnaires measuring social support, mastery, anxiety, depression, health related quality of life, and insomnia collected at baseline (T1) and after two months of use of the counselling service (T2), were also presented. The questionnaires are described in the description of study I.

Data analysis

The deductive qualitative content analysis meant all text-based communication data from both patients and the nurse were reviewed for content corresponding to Swanson's Caring Theory (Swanson, 1991). The theory is a middle range theory, meaning it is narrower in scope than grand nursing theories and thus can offer a bridge between more abstract theories and nursing practice (Barnum, 1984). The theory consists of three components that are proposed to characterise caring: *compassion*, consisting of the two processes *knowing* and *being with*; *professional competence* including *doing for* and *enabling*; and finally *uphold trust* that refers to *maintaining belief* (Swanson, 1991). Since the coding matrix was structured, only data that fit the categorisation frame were presented in the result (Elo and Kyngäs, 2008). The analysis was conducted by searching for data that matched the five theoretical processes.

6.5.5 *Synthesis of study I-IV*

To achieve greater understanding, new questions derived from conceptual definitions of “usefulness” and “importance” were applied to the results from the four studies. The concept of usability refers to the function of a service’s relation to its users, the tasks they perform, the goals, and the environment that surrounds the service (Bevana et al., 1991). This definition covers the questions of by whom, when, to what purposes and under what circumstances the examined counselling service is used. Importance refers to a state or quality of being immediately significant and meaningful, and can also concern possible outcomes, results, or effects, i.e. consequences. This definition is inspired of the dictionaries; National Encyclopaedia (2015) and The Free Dictionary (2015).

To address the questions of usability and importance of web-based counselling, the results of the four studies I-IV were evaluated with regard to these qualities. A synthesis of these findings is presented under the headings Usefulness and Importance in the result section.

6.6 Ethical considerations

All studies were approved by the Regional Ethics Review Board (reg. 549-10). Ethical considerations were made in accordance with the Swedish legislation (SFS (2003:460)) and Helsinki Declaration (WMA, 2000), including voluntary participation, informed consent, and precautions protection of personal information while processing and presenting data-

An ethical issue concerning web-based access to healthcare is the one of the “digital divide”. This term refers to people disadvantaged in their access to, interest in, or use of information and communication technology (ICT) solutions. People with low incomes or low levels of education, elderly people, those with disabilities, and minority ethnic groups are identified as having a low uptake of communication via the Internet (Cullen, 2001). More recent research discuss the digital divide as getting narrower as Internet access in general has increased, yet also warn that effective use of ICT for handling healthcare matters nowadays depends on knowledge about health and self-care (Lustria et al., 2011). By delivering care through the web, the risk is that

already underserved groups get excluded. As the implemented communication service was an addition to existing support/communication, excluding someone from this project was not a risk for exclusion from support in general.

Baker and Ray (2011) highlight some other ethical concerns inherent in online counselling (as a general phenomenon and not specifically in relation to cancer care). Difficulties in assessing clients properly in the absence of verbal cues cause a risk for misinterpretation; in addition, there is a lack of adequate processes for managing crises such as risk for a worsening situation. Therefore, participants were strictly informed that the web-based communication was not for emergency issues. In such cases they were encouraged to call.

Data collection and analysis in studies I-III was judged not to involve major ethical difficulties. Yet to recruit participants to a randomised controlled study and not use the data as was described can be considered unethical (Arain et al., 2010). This was not the intention and was not expected as the insight that the RCT was not going to work did not come until later. In study IV, the analysis was comprised of reading participants' communication, which possibly could be perceived as an intrusion into privacy. All participants were therefore informed of that possible risk and could consider participation with that knowledge.

7 Results

The results of the four studies (I-IV) are first briefly presented in turn. Subsequently, the usefulness and importance of web-based counselling from a patient perspective is described; the result is derived from a synthesis of the studies I-IV.

7.1 Study I

The results showed that 36% of patients had symptoms of anxiety, whereof 23% were categorised as having a *risk* for disorder and 13% had a *probable* disorder. 32% had symptoms of depression, 19% at *risk* for disorder and 13% had a *probable* disorder. The mean value for anxiety was 6.1 (SD = 4.3) and for depression 5.5 (SD = 4.0).

A group comparison showed that middle-aged women (30-49 years) were more likely to exhibit symptoms of anxiety. Nothing more than age (30-49 years) was associated with depression.

Associations between physical health status, insomnia, mastery, and informational/emotional support were mainly assessed as moderate ($r_s = .21 - .40$), according to Spearman correlation analyses. Only the association between physical health status and informational/emotional support was *not* significant (Table 2).

Table 2. Outcomes and correlations between independent variables within patients with haematological diseases (N=120)

	m	sd	Physical health status	Insomnia	Mastery	Info./emo support
Physical health status	37.2	11.1	2.00			
Insomnia	5.0	2.8	-.32**	1.00		
Mastery	20.3	3.9	.40**	-.21*	1.00	
Info./emo support	77.9	15.7	.10	-.35	.35**	1.00

* $p < .05$, ** $p < .01$

A logistic regression analysis revealed that low mastery and high levels of insomnia were associated with anxiety; the OR for insomnia was 1.3 and for mastery 0.7. Low mastery and low levels of informational/emotional support were associated with depression; OR for mastery was 0.7 and for informational/emotional support 0.9. The Nagelkerke R² was .37 and .48 for each model respectively (Table 3).

Table 3. Results of logistic regression analysis for patients' levels of anxiety and depression (N=120)

Variable	Anxiety				Depression			
	B	S.E.	<i>p</i>	Exp(B)	B	S.E.	<i>p</i>	Exp(B)
Physical health status	.046	.027	.09	1.048	-.034	.030	.27	.967
Insomnia	.265	.108	.01**	1.304	.211	.113	.06	1.235
Mastery	-.316	.080	.00**	0.729	-.327	.088	.00**	.721
Info./emo. support	-.023	.016	.16	0.977	-.052	.020	.01**	0.949

***p* < .01

7.2 Study II

The results revealed three main themes with additional subthemes; these are presented in Table 4.

Table 4. The results in terms of main themes and subthemes

Results	
Main themes	Subthemes
Preferences and characteristics of the individual	Appreciate the opportunity for written communication To experience motivation for web-based support To experience eligibility to web-based support
A clear context of web-based support	A clear goal with and content of web-based support A clear allocation of responsibilities around obtaining web-based support
An incorporated use of web-based services	A system adapted to the individual A system coherent with the healthcare activity

The first theme describes that certain preferences and characteristics of the individual user are crucial as to whether web-based communication for support is perceived as useful. To feel comfortable with and to appreciate the potential of the writing process are conditions for making use of the web-based communication. Another aspect is to being able to self-identify an unhealthy condition or situation and experience a need for support. Being motivated and considering oneself as entitled to support are also fundamental prerequisites to using web-based communication.

A clear and effective organisation around psychosocial support efforts in general is another prerequisite. Content and goals with the supportive communication must be clear for the user to understand to what purposes it could be used. Moreover, the responsibilities must be clearly defined to understand the structure and enable the transformation of opportunities into practice. To facilitate the realisation of support, an opportunity for two-way contact would have been preferable instead of letting all responsibility for contact

being placed on the patient or family member themselves, as this can be perceived as burdensome.

The use of web-based communication must also be a convenient and naturally incorporated part of both individual and organisational use of the Web in general. This incorporation is considered to take time, as it is understood that adapting new ways for communication is a slow process. To make it natural to seek out information or support over a web-based communication channel, healthcare needs to provide a range of web-based services. As it is natural to be familiar with the staff at the clinic, knowing the responding nurse also contributes to use of a web-based communication service.

7.3 Study III

The result is expressed as five partial interpretations related to web-based communication: a space to have their say, a consolidation of a matter, an extended caring relationship, access to individual medical assessment, and an opportunity for emotional processing. Finally, the main interpretation gives a comprehensive understanding of the phenomenon.

Web-based communication for support means a space for patients to have their say as there are fewer prohibitive factors in an asynchronous and faceless conversation. There are no time constraints, and therefore patients can feel they have undisturbed and unlimited time to express themselves at an optional time point. There are also reduced demands on adaption to what are conventional norms in oral communication. Oral conversation normally weaves back and forth in a sequence of one thing leading to another, but a written message does not have to be either continuous or adapted to such surrounding conditions. There is lesser need to take into account if one takes enough or too much “space” and the facelessness protects the person from being susceptible to signs of “disturbing” the other conversant.

As the written word endures, the patient’s question or concern rendered permanent, meaning that the conversation cannot be lost or forgotten, it gets “consolidated”. Writing is an opportunity to become aware of what really constitutes the concern, and carefully choosing a formulation that one can

revisit and revise. The message becomes indelible for the responding nurse and as the response remains, too; it is possible to read through several times.

An extended caring relationship can be enabled by the fact that the dynamics in the written media offer an unhindered opportunity to tell about and share one's experiences, even outside hospital. That the responding nurse is familiar means that the communication provides a relationship that extends beyond hospital boundaries.

Having access to medical judgment or advice in correspondence, apart from the ordinary hospital visits, means an additional way to ask for medical advice. The web-based communication means an opportunity to ask questions but also explain a health condition without having a specific question. Knowing that the potential for medical assessment exists may be sufficient for creating a sense of security.

The meaning of emotional processing refers to the room for reflection in conjunction with the writing, which may increase the understanding of one's self or one's own situation. It can also be experienced as an alleviation of a burden to put what is emotionally difficult into words, and receiving confirming feedback can create a feeling that someone really knows and cares about how you are doing; nevertheless, there is also a risk of not feeling understood.

The main interpretation indicates that the patient's influence on the communication is strengthened as the communication is asynchronous, faceless, and written. Instead of being dependent on the nurse's everyday working conditions, the communication is lifted out of this immediate context and has its origin, to a great extent, from the patient's position. Furthermore, the patient is under some protection by the lack of visibility and therefore less vulnerable to the risk of being uncared-for, in the form of a rejection response (in the facial expression or intonation). The increased, and in some sense constant, access to healthcare professionalism in terms of personal involvement and medical competence can imply a feeling of safety.

7.4 Study IV

The results from this study show that there are multiple points in common between Swanson's Theory of Caring and what is possible within the web-based communication (Table 5).

Table 5. The primary content of Swanson's theory and a summative analysis of how the web-based communication corresponds to the theory.

Swanson's Theory of Caring	Web-based communication
<p>Compassion: Knowing Knowing refers to the nurse's endeavour to understand a situation according to its meaning to the patient as a unique individual.</p>	<p>How the web-based communication is in conformity with "knowing" Patients share personal everyday life experiences or thoughts, calling for feedback from the nurse. The nurse in turn can articulate genuine interest in the patient's life as a whole, and thus evince human compassion.</p>
<p>Compassion: Being with To be with involves the nurse giving of herself and providing physical, psychological, and emotional support to the patient.</p>	<p>How the nurse's "being with" functions in the use of web-based communication When patients expose their vulnerability and the nurse responds in a supportive way by expressing empathetic attention and confirmation, being with becomes possible.</p>
<p>Professional competence: Doing for Doing for implies the nurse doing what the patient cannot do for him-/herself given the actual illness situation.</p>	<p>The process "doing for" through web-based communication The responding nurse is limited to organising practical arrangements like phone calls, referrals, etc., after explicit requests from the patient or if the patient is considered in need of it.</p>
<p>Professional competence: Enabling Enabling is about how the nurse empowers the patient by facilitating the path through the disease. This means strengthening the patient's participation by enabling the patient to take control.</p>	<p>How the web-based communication permits "enabling" The nurse's transferring requested information (e.g. about the disease) in order to strengthen the patient's control of the situation. To enable is also about giving advice on managing emotionally difficult situations and thus strengthening the patient's ability to cope.</p>
<p>To uphold trust: Maintaining belief By striving to know, be with, do for, and enable the patient, the nurse can maintain the patient's beliefs. It is about holding patients in high esteem and believing in their ability to achieve their goal.</p>	<p>How the nurse can maintain a patient's belief by use of web-based communication Maintaining beliefs presupposes that the patients reveal their innermost thoughts in the case of meaning. The nurse then gains an opportunity to encourage the patients' self-esteem.</p>

Nursing compassion substantiates when patients share personal matters and the nurse receives an opportunity to explicitly display genuine interest and understanding.

Knowing can be made possible for the nurse by the patients' sharing parts of their everyday life. Patients explicitly express not only illness-related issues but also what happens in everyday life in the written messages. This can be seen as an invitation from the patient's side for the nurse to gain insight into the patient's life and thus becomes an opportunity to understand the patient.

For the nurse, *being with* is possible when patients write about health and wellbeing. Similarly to sharing how everyday life is progressing, patients communicate physical, emotional, and social worries. Through explicit expressions of confirmation and validation of the patient's experience, the nurse can "be with".

Nursing competence appears when patients ask for or are in need of information, advice, and emotional support. The nurse can uphold trust when compassion and competence is attained and patients share their innermost feelings.

Because of the physical distance and time delay, the nurse's tangibly *doing for*, such as daily care activities, is not possible. Nevertheless, patients' explicit requests for direct actions make some kind of doing for possible.

The nurse's ability to *enable* the patient's sense of control of the situation is achievable when patients request information and advice about how to do the right thing in relation to their illness. This is evident by patients' asking questions related to physical concerns but also by exhibitions of emotional worries. A supportive response can be a combination of confirmation of what is bothersome and information that can ease anxiety.

The need for the nurse to *maintain beliefs* becomes apparent when a patient articulates a lack of hope and faith. To respond to an explicit expression of lack of hope is about being both realistic and conveying a sense of self-confidence.

7.5 Usefulness of a web-based counselling service

Usefulness relates to questions of for whom the web-based counselling is appropriate or suitable, when or to what purposes it is used, as well as under what circumstances it is usable.

For whom web-based counselling is appropriate

The question of for whom a counselling service is useful has to do with what support needs the individual has (II). From an external perspective, it is the patients who exhibit symptoms of ill health who are in need of support. This need is expected to be reinforced if the demonstrated ill health is combined with low internal resources and/or low levels of external support. The first study revealed that females in the age group of 30-49 distinguished themselves as particularly vulnerable for experiencing anxiety. In addition, it seems reasonable that those patients having a lower sense of mastery, increased insomnia, as well as low level of informational and emotional support, also are vulnerable for experiencing anxiety and/or depression (I).

On the other hand, as the service is patient-driven, an external judgment of a patient's need for support is not decisive. The individual must *experience* a need and also have a motivation to actively seek support. For the supportive communication to be realised, the individual must identify the concern, experience a desire for support, feel entitled to the resources, and then request what the service offers (II). This is also confirmed by the main reason stated by patients for declining to participate in study III/IV: not experiencing a need for support.

There must not be a contradiction between an external assessment of support needs (due to symptoms of ill health) and the individual's own motivation, but these may reasonably coincide. In addition to the issues of ill health, need, and motivation, some individual preferences and characteristics are necessary for the web-based counselling to be seen as useful. To be comfortable with the written media is a condition for appreciating the service (II). Some patients simply prefer to write rather than make phone calls. One significant reason for appreciate writing is the sense of getting the space to say what one wants to say without disturbing the healthcare personnel. The fact

that the communication is both asynchronous and faceless seems to limit some prohibitive factors that normally exist in oral conversation (III). Likely, users are thus those who appreciate the writing process in itself and the sense of anonymity it means to not have to hand over their face or voice. Probable users are also those benefitting from the practical surrounding circumstances: free space and no time limit.

When and to what purposes web-based counselling is used

The service is used when the patient is not in hospital, as the only alternative to the phone. Thoughts and worries tend to occur between visits, particularly when treatment is not very intensive, and it is time for the patient to relax. It is possible to send a web-based message when questions or concerns arise while being at home and when it suits patients (II, III). Those patients diagnosed between 13-36 months previously were significantly more frequently seen in the category with symptoms of anxiety (I). It is not self-evident how to interpret this, but one can reasonably expect that different stages in the disease and the treatment affect patients' need for support when at home. The time after completion of the medical treatment is for example highlighted as especially difficult as it is time to return to everyday life (II).

Requesting disease-oriented medical information is one way to make use of the counselling service (II, III, IV). Another use is to put into words what is hard and then send it to someone else, thereby relieving oneself of the burden (II, III). To narrate about more everyday life (IV), to share emotions and receive emotional support, are additional purposes for using a counselling service (III, IV).

Under what circumstances is web-based counselling useful?

For a web-based counselling service to be useful, certain prerequisites within the organisation must be met in addition to the necessary personal characteristics of the users previously mentioned. The service must be part of a comprehensive set of offered supportive activities. The function and objective of not only the counselling service but the whole range of psychosocial support that is offered should be well-defined. Otherwise, the web-based service is solitary and without anchorage and it is unclear what is reasonable to expect or request from it for the patient (II).

Similar to being part of a comprehensive supply of psychosocial support activities, there needs to be a comprehensive inventory and use of web-based services (e.g. an informative website and additional communication functions) with which the counselling service can be associated. This condition is important for the whole communication system (Mina Vårdkontakter) and the specific counselling service in order to become a natural path for communication or the handling of healthcare matters (II).

Under current research circumstances, patients were given an opportunity to create a relationship with the responding nurse. It is not impossible that this was an additional necessary circumstance for use by certain patients.

7.6 The importance of web-based counselling

The importance of web-based counselling refers to its meanings and consequences as experienced by patients.

Meanings of web-based counselling

The counselling service means a possibility for patients to initiate and direct the communication and, without hindrances, focus on what they consider important (III). The fact that the patient controls the service does, however, not only entail benefits; it requires the ability to self-identify the problem or assess one's own need for support, as well as the strength to take that initiative. For those not having these strengths, it is difficult to achieve the meaning of having this free space (II).

Web-based communication means decreased demands related to what is proper according to ordinary social conventions, perhaps important in light of the greater demands resulting from patients' taking responsibility for the communication to occur in the first place. Social conventions such as taking an appropriate amount of space as in an oral conversation can be overridden by the lack of time restrictions and there being no face-to-face meeting (III). That the communication is not restricted by time and patients choose when to write, implies convenience and a sense of independence in relation to time (II, III). It also means a possibility to take as much time as wanted, with a lesser risk of feeling bothersome (III). The facelessness means the patients are less vulnerable to the responding nurse's reactions. In physical meetings

and during phone calls, there is a risk of not being treated well, which the patient is somewhat protected from in the web-based communication (III).

The communication within the counselling service can be experienced as emotionally supportive. The self-reflection inherent in the writing process may increase the understanding of one's self or one's own situation (III). Instead of going home and brooding, it can be experienced as an alleviation of a burden to put what is emotionally trying into words (II, III). A supportive response to emotional concerns can be a combination of confirmation of what is bothersome, information in order to ease worries, and attempts to reinforce the patient's trust in his or her own ability (IV).

In addition to emotional support, the counselling service means access to nursing competency, including individual medical assessment and by extension, help with practical concerns (III, IV). Besides, it may entail a sense of safety to have this additional constant access to medical advice in correspondence form apart from the ordinary hospital visits (III).

That the messages in written text endure means the patient's issue becomes indelible for the responding nurse (III). That in turn means the nurse is obligated to deliver both adequate information and a caring response. A failure in this regard becomes very apparent and can mean an obvious risk for non-caring (IV).

Web-based counselling—consequences for the patient

According to data from the comprehensive RCT study⁵, no evidence was given for the hypothesis that the web-based counselling contributes to increased mastery or social support, nor lower levels of psychological distress or insomnia, that is; there were no significant differences in change in any measure.

However, there are some qualitative data that support that the web-based communication may have consequences for the patient. The counselling service, according to the qualitative results, increases the availability to pro-

⁵ Variables between intervention and control group were tested for significance. Due to small sample size, short intervention time, and the relative weakness of the intervention, these results were not considered publishable.

fessional caregivers' competence and caring approach (II, III, IV). This was yet not validated by the data measuring patients' perceived levels of access to informational and emotional support.

With reference to what is communicated, asking questions and receiving information (III, IV), one reasonable consequence is that users become more informed. Patients being better informed or more knowledgeable can form the basis for an increased sense of control/mastery. However, there is no quantitative data showing that the web-based counselling increases mastery.

The communication accommodates sharing emotions, emotional confirmation, and validation (III, IV). The inherent aim within such processes is to relieve distressful feelings, something that is also expressed by the informants (III). One probable consequence, in the long run, could be alleviated distress or symptoms of illness. Then again, there is no quantitative data supporting that use decreases levels of anxiety, depression, or symptoms like insomnia.

8 Discussion

This session consists of two parts: discussion of the method and of the result. Methodological considerations are structured out of different aspects of the concept “quality”. Research is characterised by a systematic search for knowledge, which aims to arrive at knowledge that is as trustworthy as possible, and this depends on the quality of this systematic process. The result is discussed on the basis of what new knowledge has been generated.

8.1 Methodological considerations

Quality in research is commonly described in terms of different concepts within quantitative and qualitative research: internal validity/credibility, external validity/transferability, and reliability/dependability. In common for the concepts is the objective to serve as a basis for judgment whether the results are trustworthy or not, and to what extent the results can be assumed to apply to other contexts. An evaluation of the quality of the four studies is made based on the aforementioned aspects: internal validity/credibility, external validity/transferability and reliability/dependability.

8.1.1 Study I

Internal validity

Internal validity refers to absence of systematic errors (bias) in quantitative research. Good internal validity means that what we intended to measure really was measured (Creswell, 2009). The first threat to internal validity is the cross-sectional design, in comparison to a longitudinal design, as there is a lack of clarity about which variable is the cause and which is the effect. The researcher’s understanding and choice of relevant predictor and confounding variables is therefore important for internal validity, according to Burns and Grove (2005). The variables were chosen at an early stage and primarily based on the purpose to study the effects of the counselling intervention. To examine the variables’ interrelationships was a decision that came later, and in hindsight they were not optimal in order to “identify vulnerable individuals” in clinic care; for health care personnel to be watchful

of individuals with low internal resources is perhaps difficult and thus impracticable. The existence of confounding variables, e.g. disease progression, influencing the dependent variables is also probably high.

Internal validity in this study is also determined by the specific measurements chosen. As both MISS (Broman et al., 2008) and HADS (Vodermaier and Millman, 2011) are used as clinical diagnostic tools, they can be considered as relatively secure in terms of accuracy in grasping the actual phenomenon being studied. HADS is a frequently used questionnaire and the results are therefore comparable with those from other studies. The cut-off chosen for HADS was in concordance with a recommendation by Bjelland et al. (2002).

To measure quality of life is generally more controversial because of difficulties in finding good operationalisations of a comprehensive concept such as “quality of life” (Walters, 2009). The study focussed only on the physical health component in SF-12 and not the total score. This choice was based on searching for a measure of physical health as a description of the progression of the illness. In hindsight, a better choice for this purpose could have been to measure performance status, e.g. Karnofsky Performance status, which measure patients’ physical ability to survive severe treatment (Karnofsky et al., 1948).

The Pearlin Mastery Scale is a questionnaire based on an operationalisation of a very elusive phenomenon: sense of mastery. Originally, the scale was developed for healthy individuals, and as such mastery is a state and not a changeable trait (Pearlin and Schooler, 1978). In the context of diseases, mastery, however, is believed to be disrupted (Pudrovska, 2010). In the beginning of this research project, this questionnaire was therefore considered appropriate for measuring mastery as a trait possibly strengthened by support from a counselling service. Although there was some support for the expected associations between mastery and the other variables, I today consider this as an unsuccessful choice. As mastery is so closely related to personality, it is doubtful whether any support can make a patient feel control of a future threatened by a disease that is not self-inflicted (such as e.g. lifestyle diseases).

MOS-Social support scale measures the access to support that individuals perceive themselves as having. The sub-scale of interest in this study was the one measuring informational/emotional support because this was what the counselling service intended to bring. Given the discussion of needs and motives for support, it would have been more valuable to measure “desire for support” rather than levels of existing support.

External validity

External validity is about the extent to which study findings can be generalised to the population from which the sample was drawn (Creswell, 2009). Internal validity is a prerequisite for external validity. As this is highlighted as a weakness in the present study, the external validity is also affected. Moreover, external validity can be promoted by appropriate sampling strategies and high response rates (Kazdin, 2003). The sample within this study was a convenience sample and not an independent random sample, which would have been preferred in order to be able to draw inferences about the prevalence rate in the population. The relative similarity with other studies’ results possibly testifies that the sample was still somewhat representative. The assessment of associations is less influenced by the sample strategy, and the external validity in that regard is therefore not threatened in the same manner.

Reliability

Reliability refers the result is being developed in an accurate way, with no uncontrolled error. In quantitative research, reliability is equal to reproducibility (Kazdin, 2003). The reliability in terms of internal consistency was calculated but only reported for the questionnaire measuring informational/emotional support, though this measurement demonstrated probable redundancy (Cronbach’s alpha = .96), and ceiling effects (the distribution was skewed to the left). The other questionnaires demonstrated no obvious weaknesses in terms of reliability. In the Mastery scale, two of seven items are negatively expressed, meaning they include the word “not”, which is not recommended according to Streiner and Norman (2008) as this makes it difficult for the respondents to understand how to respond. Moreover, there is no direct reason to suspect weaknesses in the reliability.

8.1.2 Study II

Credibility

In qualitative research, “credibility” is normally used interchangeably with internal validity. Credibility refers to how the research process addresses the intended focus and the consistency and richness of the findings (Guba and Lincoln, 1982). An established relationship of trust between the informant and researcher can enhance the credibility (Lincoln, 1995). In this regard my own, albeit outdated, experience of haematological care may have been positive for the credibility of my interest in and understanding of the patients’ stories. Credibility can also be ensured by data triangulation, or “member checks” (Lincoln, 1995). Member checks (i.e. control of how the informants “recognise themselves” in the outcome of the analysis) were not utilised in this study. However, in the synthesis in the overall thesis, there is a mixture, i.e. triangulation, of perspectives that might strengthen the credibility in some parts of the results. As a doctoral student, you are under the scrutiny of supervisors, which also can be understood as a sort of monitoring of the credibility.

Transferability

Transferability is about to whom the results can be applied. By presenting a thick description of the settings and methods, the transferability to other contexts can be determined by the readers (Lincoln, 1995). For obvious reasons, it is therefore difficult to be self-evaluative in terms of transferability. The sample is heterogeneous, as patients, family members, diagnoses, and other disease characteristics vary. This may create a lack of clarity about who the results are valid for, but at the same time it may possibly widen the borders for the transferability.

Dependability

Dependability refers to factors of stability in the design and the performance of the analysis process (Guba and Lincoln, 1982). It can be established by, in detail, reporting the research process in the study to enable an external researcher to repeat a somewhat similar process. According to Graneheim and Lundman (2004), interviewing is an evolving process during which the interviewer acquires new insights into the phenomenon of study that can subsequently influence follow-up questions. This evolving process was certainly the case in study II. The purpose of this study came to cover two perspec-

tives: demands on the organisation and conditions within the individual user. Having two foci may have impeded the dependability. In a content analysis, the coding process is about organising quantities of text into logical patterns of fewer classifications. Well-saturated data facilitates such categorisation and abstraction (Elo et al., 2014). Data from eleven patients and six family members was a mixture of entrances to a two-tier phenomenon, which reasonably complicates the dependability.

8.1.3 Study III

Credibility

To understand is, according to Gadamer (1994), to be able to apply a certain meaning to a situation or phenomenon. Our pre-understandings are necessary conditions of understanding; therefore all understanding presupposes interpretation (Ibid.). As a consequence of this epistemology, the analysis process is in a way reversed relative to content analysis. The hermeneutical circle is about starting with a vague anticipation of the whole that is revised the more we engage with our data. This meant the suggestions of partial interpretations (patterns of parts/themes) was not primarily derived from data, but initially more from the researcher's mind and understanding, and then validated back against the data. Larsson (2005) says that a result's richness in meanings is fundamental to its credibility: the more nuances highlighted, the greater precision in the interpretation, without losing the requirement of a clear structure (Ibid.). The results are quite close to data that, in combination with several quotes, might give the reader a rich picture of the phenomenon in focus. On the other hand, the interpretations are not very ventured or innovative.

Transferability

In order to transfer the results from study III to other situations, it is necessary to keep in mind that extra time and resources related to the provision of counselling were added. Participants' exhibited problems are reasonably typical of the patient group (anxiety, depression, physical problems, and medical questions). Yet the participants received additional information about the intervention and were explicitly encouraged to use it. Such circumstances led, as one would expect, to more frequent use than would otherwise

have been the case. On the other hand, what is transferable from the result are the possible meanings rather than the frequency of use.

Dependability

An insight into the researcher's preconceived ideas should be of importance for the judgement of the result's dependability (Larsson, 2005). As in most intervention studies, there was an expectation of positive experiences of the web-based counselling service. It is not impossible that this expectation, in combination with grateful informants, steered the result in an overly positive direction. To be self-critical, that the web-based communication lacked non-verbal cues and that the time-delay could be considered aggravating, were not focussed on in the analysis for further discussion.

8.1.4 Study IV

Credibility

In a deductive content analysis, the credibility is steered by the structured matrix used for the analysis. Hsieh and Shannon (2005) state there are some inherent limitations in approaching the data with somewhat strong bias. They argue that the researcher might be steered to search for only evidence that supports the theory (Ibid.). One can also consider credibility in a deductive procedure as similar to how internal validity is achieved through use of a measurement in quantitative research. Does the chosen theory really grasp what is in focus for the study? I think it does, but at the same time, different caring theories could have been used for the same purpose.

Transferability

As the analysis focussed on principals of content and how things are expressed and responded to rather than typical "haematological concerns", the results can be valid for also other healthcare context. The transferability can therefore be considered to be fairly good.

Dependability

The precision of the results is perhaps more evident in a deductive analysis, as the same analysis is quite easy to reproduce in comparison to an open-minded analysis. Swanson's theory was used as a tool, and this tool remains for future research as well.

8.1.5 A summation of the quality of the studies

In conclusion, the internal validity/credibility of the studies has been affected by the phenomenon: the counselling service, during the current research circumstances as it developed and became more personalised than expected from the beginning. More resources than reasonable in a standard care activity were applied to research participants; therefore, a relationship was created between the responding nurse and the participants. It motivates the question: What has actually been examined? If we are open to understanding the phenomenon on the basis of these assumptions, the results are still reasonable due to, for example, consistency with other research findings.

How the studied phenomenon is defined also affects the external validity/transferability: for whom are the results valid? Besides the first study, the results of which are linked to the specific diagnostic group, the other results can possibly be transferable to other critically ill patient groups and healthcare clinics.

Finally, the reliability/dependability of the results can be considered to be strengthened by several studies focussing on the same phenomenon, although this has evolved.

8.2 Discussion of the results

The aim of research activity is to gain knowledge, first and foremost new knowledge: to shed light upon something we did not know very well before. After the discussion of usefulness and importance, there is a brief reflection on the connection to theory. The final goal is that the new knowledge can function as a basis for improvements of reality, i.e. clinical practice. The latter is presented as clinical implications. Lastly, proposals are presented for future research.

8.2.1 Usefulness of a web-based counselling service

For whom web-based counselling is appropriate

The first section of the result concerns the question of for whom the web-based counselling can be useful. Knowledge on which patients a web-based

counselling service can reach and not is important as this can form the basis for how to propagate such a service. It also gives a clue as to which patients to be extra watchful for, as they probably will not make use of such a service and hence might need to be encouraged to use other support resources or channels for communication.

The patient experiencing illness is part of the answer to the question of for whom web-based communication can be useful. Newly diagnosed middle-aged females appear to be an exposed group for exhibiting symptoms of anxiety according to this result, similar to other research as well (Linden et al., 2012). Having symptoms of insomnia, a lower sense of mastery, and perceiving low level of informational/emotional support are also risk factors for developing distress, according to study I. This is in some agreement to also other research; a review by Allart et al. (2013) demonstrate that sense of coherence, self-esteem and health locus of control, certain coping strategies, and social support are associated with better quality of life among patients with haematological diseases. Specifically mastery has been found to be a significant predictor of pain resolution status (but not fatigue) among patients with cancer (Byma et al., 2009). The variable social support has proven to be associated with better quality of life and lower levels of fatigue in patients with Hodgkin's Lymphoma (Soares et al., 2013).

In addition to viewing the results from a clinical perspective, there was a desire to test the suitability of the variables as outcome measures in an experimental trial of the web-based counselling service. One late objection, supported in previous research, is that mainly mastery (Hochhausen et al., 2007; Neipp et al., 2007) but also support (Linden and Vodermaier, 2012) are difficult concepts to measure and interpret. Instead Ventura et al. (2013), argues supportive interventions should be evaluated according to the theoretical basis for the change inherent in the specific support intervention. Thus one conclusion is that concepts more clearly related to the web-based counselling service, could be recommended. An evaluation could focus on e.g. the availability of information/contact, or satisfaction and trust in what is communicated.

As the studied counselling service is patient-driven, the next question addressed in the result concerns which patients *experience* a need for support.

Linden and Vodermaier (2012) point out that it is when there is a mismatch between desired and perceived support that an experience of need arises. If a need is experienced, it must be combined with a motivation to actively reach out for support for a web-based counselling service to be useful. Taken to extremes, neither symptoms of ill health, experiences of illness, nor mismatch between desired or perceived support is equivalent to being *motivated* to actively reach out for support. Prior research presents different results on what characterises those who actively make use of a web-based channel for support: McDowell et al. (2011) found that female gender and a more positive attitude to help seeking characterized those (patients with cancer) who were more likely to utilize support. Børøsund et al. (2013) demonstrate that users of an e-message function within a multifunctional supportive application are characterised by high levels of depression and symptom distress and low levels of support. But Nijland et al. (2011), on the other hand, show that such support (provided to patients with diabetes) is most frequently used by those with *least* health problems, in combination with high education.

It seems fair to assume, from the results of this study in combination with prior research, that those who are females, younger, experiencing somewhat distress or illness, and having lower levels of mastery and/or informational/emotional support possibly can find a web-based counselling service useful. Being comfortable with writing may well be consistent with a high level of education. Consistent with the latter, Paul et al. (2011) demonstrate that access to the Internet and likelihood of using the Internet to search for information was associated with higher education among patients with haematological cancer. Higher education, as well as lower age and higher income, were significant factors for cancer patients' willingness to use e-mail communication with the healthcare providers according to a study by Dilts et al. (2009).

Not wanting to be bothersome also seems to be a characteristic for some patients who experience the web-based support as useful. This is consistent with psychological reasoning about personality and Internet usage, wherein introverted people can prosper thanks to the secure environment that the faceless asynchronous meeting confers (Amichai-Hamburger, 2005).

Taken together, one conclusion based on this result in combination with the study by Paul et al. (2011) is that healthcare needs to be vigilant regarding vulnerable individuals as well as to offer a wide range of supportive activities. Such a strategy enhances the ability to capture patients with different kinds of ill health, unmet needs, different communication preferences, personality, and capacity to reach out for support.

Family members were only included in one study (II), but form a group that experiences psychological distress at levels comparable to or higher than the patients themselves (Beattie and Lebel, 2011; Molassiotis et al., 2011; Rhee et al., 2008). The result by Molassiotis et al. (2011) also demonstrates that one-third of family members experience unmet needs, in comparison to one-fourth of patients. According to study II, family members perceive themselves to be less eligible for support, as it is the patient who should be in focus. This is close to “not wanting to be bothersome”, and therefore why a web-based medium might make it easier for family members to get in touch with a supportive nurse. Kinnane and Milne (2010) summarise the Internet use of informal carers to patients with cancer, and declare they search for information and support mainly via the public Internet and support groups, but they desire to a greater extent contact with the patients’ formal caregiver via e-mail. A study by Merckaert et al. (2013) indicates that family members’ desire for support is negatively associated to age and education, but increases with higher levels of distress. These are obvious reasons to examine how this group as well can be given access to web-based support without using the patient’s identity, as well as usefulness and importance from their perspective.

When and to what purposes web-based counselling is used

Another aspect of usefulness is the question of when the service is used. From a national political perspective, there is great anticipation that IT solutions will increase the availability of care for patients (Socialdepartementet, 2005). This is mainly related to patients outside of hospital. The telephone has existed for a long time for that purpose, but there seems to be significant differences between written, asynchronous contact and spoken contact in real time. The current results demonstrate that some differences seem to exist regarding freedom in time and space and the sense of anonymity, aspects also confirmed in prior research (Moore and Sherwin, 2004; Wibe,

Hellesø, et al., 2012). Technical access to the Internet has been an earlier issue (Socialdepartementet, 2005), but in Sweden this is a rapidly decreasing problem. Digital access has been discussed as an ethical issue, wherein those who have not adapted information technology are described as undemocratically excluded (Cullen, 2001). Such reasoning, however, presupposes that the technology will replace existing opportunities for contact, which in all likelihood is rarely the intention. Rather, alternative channels of contact should be seen as a way to satisfy more individuals' different preferences, and thus defend democracy or fair access.

To what purposes the service is used also has to do with usefulness. To ask for medical information is quite straightforward, and is also consistent with how the studied service was actually used. This particular use is expected, uncontroversial, and requested (Eysenbach, 2003). The results demonstrated an additional area of use: writing in order to narrate and express emotional or social concerns. This use is also in some accordance with existing research (Grimsbø et al., 2011; Grimsbø et al., 2012). To advance the state of knowledge, we still need to find out more about what is required for such use to be realised, given that we consider such use positive. This argument is further developed below.

Under what circumstances web-based counselling is useful

The last aspect of usefulness concerns under what circumstances a web-based counselling service is useful. Increasing access to emotional support and information is a recurrent clinical implication in studies exploring unmet needs among patients with haematological diseases (Hall et al., 2014; Swash et al., 2014). This is somehow easy to conclude. According to the results from this thesis, it seems to be a bit more complicated to realise supportive actions. Supportive communication through a web-based counselling service requires that users, besides being able to identify the own needs and being motivated, understand the structure of how support is realised. It does not seem to be enough to make such a feature available; to achieve true functioning there needs to be a clearly defined structure of supportive resources and an overarching context of Web services.

For that purpose, it is important to consider where in the healthcare structure this function should be positioned. A counselling service is almost by nature

open and accessible for any patient registered at the clinic, as it should be. Under these research conditions, however, all enrolled patients formed to greater or lesser degrees a relationship with the responding nurse. This is hardly possible within a central counselling service in a real-life scenario, and is also highlighted as a problem according to transferability in study III: Under what circumstances and for who is the result valid? We need to separate and explore more specifically what it takes to provide “unrestricted clinic-based web-based counselling” and “web-based communication with a known nurse” respectively.

8.2.2 *The importance of web-based counselling*

The abovementioned relational factor with impact on transferability; if patients have a relationship with the responding nurse, or not, has also influenced the found meanings. Some identified meanings and consequences certainly derive from web-based counselling with a traditional central location on a clinic, reachable for a large number of patients. But other meanings are reasonably influenced by the relationship which developed between the project nurse and the recruited participants. This is important to keep in mind when discussing meanings and consequences.

Meanings of web-based counselling

The absence of time pressure and sense of unlimited space within the web-based communication enable the patient to steer and direct the communication, to focus on what the patient wants to share. Due to social conventions, this is not self-evident during physical face-to-face meetings. The positive aspect of the sense of “anonymity” being associated with not having to reveal one’s face is documented; it can invite a patient to go straight to the point and disclose what is bothersome (Baker and Ray, 2011). In a similar way, online counselling within the field of psychology is proven to allow a disinhibition which facilitates patients’ expressing openly, and reducing the anxiety surrounding certain issues (Richards and Viganó, 2013).

From a caring perspective, the personal meeting is considered as the core of nursing care (Dahlberg and Segesten, 2010; Peplau, 1952; Swanson, 1991; Watson, 1988). Explicitly or implicitly, this refers to physical meetings in real time, as it involves, for example, body language and access to visual and

verbal cues. That healthcare personnel experience compatibility between the usability of a system and working practices is important for a successful introduction and use of information and communication systems (Gagnon et al., 2012). In the meantime, this result as well as others (Wibe, Ruland, et al., 2012), demonstrate that communication within a web-based medium actually has a potential to be caring. The result from the deductive analysis showed several signs of congruencies between Swanson's Theory on Caring (Swanson, 1991) and how it is possible to communicate within a web-based counselling service. Taken together, there seems to be a real opportunity that nurses can find use of such communication as congruent with their core mission. But to what extent this necessitates a strong relationship between those communicating remains unclear from this result.

A question that should be highlighted is whether the sense of anonymity is possibly the same for the responding nurse. As courage is needed to confront patients' existential concerns in traditional face-to-face encounters (Källerwald, 2007; Thorup et al., 2012), encountering patients is perhaps eased by a corresponding sense of anonymity for the nurse.

Emotional processing has a two-fold meaning: on the one hand, writing is a reflective process, powerful enough in itself to be used as a therapeutic method (Lepore and Smyth, 2002). On the other hand, to receive explicitly expressed emotional support by the responding nurse, can mean being seen (confirmed) and having one's story validated. This is also a central part of a caring approach (Dahlberg and Segesten, 2010). If the nurse fails in this regard, i.e. does not see, hear, or take patients seriously, there is a risk that patients feel neglected and poorly cared for (Ibid.). Since written words endure, not only successful responses but also failures become exceptionally obvious.

With regard to the risk for non-caring, the lack of knowledge that Schnur and Montgomery (2012) highlight as hindering health professionals to enforce web-based communication with patients does not seem unjustified. Meanwhile, to achieve at least some degree of caring requires quite small explicit expressions, one suggestion from study IV is to: 1) See the person behind the text; 2) Show interest and ask questions; 3) Share the tone in the message, positive or negative; 4) Repeat, confirm and validate/guide further

the patient's experiences and emotions; 5) Encourage further contact; 6) Act according to the patient's request or suggest a different course of action. These recommendations should be further researched and discussed with clinical professionals to determine if they have bearing in practice.

Web-based counselling—consequences for the patient

In terms of consequences, the result demonstrates that patients experience increased access to professional information and support; however, this could not be shown in the quantitative data measuring these aspects of social support. That the selected variables and measurements are theoretically linked was a base point and this thesis has statistically confirmed some of these associations, but not that the studied counselling service was a significant influencing factor. Only two studies have been found that evaluate the effects of web-based counselling/communication to patients with cancer: the study by David et al. (2011) found no significant improvements in distress or quality of life. Børørsund et al. (2014) found some effects on depression; mean change -0.69 , $p < .03$ on the Depression-scale in HADS. The effects were, however, less than those found for use of a multifunctional system including a similar communication channel and additional features.

Whether it is relevant to discuss consequences in terms of effects depends on how we regard the examined web-based counselling service: as a healthcare intervention or simply as an additional means for communication? If it is seen as a distinct psychosocial supportive intervention, it could be evaluated in a "traditional" manner: using a large enough and more homogenous sample, more appropriate variables, and an allocated and definite counselling session with specific actions and well-defined objectives. Otherwise, if we are interested in "web-based communication with a named nurse", one proposal is to place the possibility for such communication at the so-called contact nursing level, i.e. patients can communicate with "their own" named nurse. Then the question of consequences in terms of measurable health outcomes will not be equally relevant as such communication becomes individually tailored and the objective is then less clear. The communication is likely confounded by the physical meetings at hospital visits, as well.

8.2.3 *A reflection on the use of theory*

Some different nursing or caring theories are referred to. Dahlberg and Segesten (2010) and Watson (1988) are two examples of descriptive theories that define the consensus concept of caring.

Peplau's theory on interpersonal relations (Peplau, 1952) is referred to in study III, largely as an example of how the core in a 60-year-old theory is consistent with what is described as central in a study of relatively modern web-based communication: the relationship.

In study IV, Swanson's middle range theory on caring (Swanson, 1991) is used to show how what can be performed via the web-based medium is consistent with a quite classical definition of caring. Swanson is a follower of Watson's who is the creator of a grand theory in nursing telling what nursing is, and what a nurse should work with, albeit at a high abstraction level (Watson, 1988). The reconnection to the citation of Dahlberg and Segesten (2010) in the discussion is intended to highlight the consistency between what seems possible to achieve within web-based communication and more traditional face-to-face encounters.

The actual use of theory, or rather theoretical concepts, is somewhat normative, i.e. empirical data are compared to theoretical definitions of ideal conditions for caring. The intention is to show the correspondence between the use of a web-based counselling service and caring, and it also confirms the affiliation to the scientific field of nursing. Other terms, resources and symptoms, have been used to describe expected associations between causes and effects inherent in the web-based counselling. This was due to the adjustment to previous research and a wish to measure effects.

9 Conclusion

The main conclusion is that there is caring potential within web-based communication between patients and a responding nurse located at the same clinic.

Some patients probably find a web-based counselling service useful; those who experience distress while having low mastery and/or low levels of support and are comfortable with writing endorse using web-based communication for support. Appreciation of the practical benefits and the facelessness inherent in the asynchronous meeting facilitates asking questions, narrating concerns, and receiving emotional support outside the hospital.

Those patients capable of using the open-ended environment the web-based communication entails can direct the communication without the restrictions that ordinary social conventions require. The increased and constant access to personalised information and caring communication can thus provide patients with a sense of safety. The information per se and the emotional processing has a potential to make patients more informed and to alleviate negative emotions.

The written expressions of caring have, moreover, several similarities with what is defined as caring in traditional physical meetings. The fact that the messages are written, enduring text makes the patient's issues indelible to the nurse who is obliged to respond in an explicitly caring way.

Not all patients have the same preferences when it comes to communication. The importance from a patient perspective can also differ, as not all patients have the same need for support or caring communication. For a web-based counselling service to be useful and effective, it must be part of a comprehensive set of supportive activities, which in turn must be fully clear to and adopted by the users. When striving for patient-centred healthcare, alternative paths of communication and a variety of support efforts should, therefore, be provided to patients. When possible, this should be offered to their family members as well.

Where to place this communication in the healthcare structure is not unquestionable, either as a central counselling service or at a nurse-patient level. Regardless of location, there are no longer any practical obstacles to providing either web-based counselling or web-based nurse-patient communication. On the contrary: the technical and legally secured solutions exist.

Finally, to achieve those advantages web-based communication can confer, healthcare should make efforts to make such use possible. To successfully encounter patients through a web-based medium, nurses need to learn to convey and explicitly express a caring approach in written communication.

10 Clinical implications

On the basis of this thesis, some suggestions can be made on how to improve clinical care:

- Healthcare needs to be vigilant regarding vulnerable individuals. By routinely identifying each patient's health status, support needs, and preferences for support, the realisation of supportive care is facilitated. Web-based counselling might be useful for some patients, but healthcare should offer a wide range of supportive activities in order to satisfy patients' different preferences and needs.
- Introducing and enabling a possibility of web-based counselling give patients a greater access to caring communication while being outside the hospital. Necessary is a clear structure of support resources in general and web-services in particular for use to become a natural activity. What support resources exist, what they consist of and mean, as well as how support is realised, should be clearly described to patients. Healthcare professionals should ensure that patients are well aware of this. In the end, the structure of resources offered is a question of leadership and strategic work with support to and rehabilitation for patients.
- Healthcare should be aware of family members' needs as well, as this is a vulnerable group and persons of great importance for the ill patient. The minimum personnel can do is to ensure that also loved ones understand what resources are available and how they used.
- Taking a patient perspective may mean deviating from an old-fashioned nursing perspective. Web-based communication seems to imply a new way to deliver compassionate and competent care that nurses should take possession of. This, in turn, causes a need for nurses to acquire new skills in terms of how caring can be explicitly articulated in writing. This could be learned through hands-on practice, for example through written exercises targeted towards the pro-

posed recommendations to 1) see the person behind the text; 2) show interest and ask questions; 3) share the tone in the message, positive or negative; 4) repeat, confirm and validate/guide further the patient's experiences and emotions; 5) encourage further contact; and 6) act according to the patient's request or suggest a different course of action.

II Future research implications

Some proposals for new research questions have been made in the discussion. These are summarised and expanded below:

- One important question concerning healthcare development is how the range of web-based communication channels should be organised. Should healthcare provide comprehensive central consultative communication at the clinic, patient to nurse communication, and even family member to nurse communication? Possible and crucial qualitative research questions are what these different alternatives mean to patients, family members, and nurses. Quantitative research questions could focus on the outcomes of such possibilities for communication, provided that the objectives of the various options are clearly defined. From an organisational perspective, the question of resource consumption would also be interesting. Observations could provide answers to whether and how issues are addressed and work time gets redistributed.
- How healthcare can identify vulnerable patients and, as far as possible, prevent these individuals' developing symptoms of ill health is another important issue. A potential research question is to what degree healthcare personnel are aware of characteristics typical for those patients with low internal and external resources. This could be focussed on by using a qualitative approach: how is such awareness constituted? Moreover, quantitatively: what do personnel consider in that regard when meeting patients, and to what extent do they consciously reflect on this?
- How can healthcare develop contingencies to capture patients who already experience illness but lack the ability to reach out actively for support? This problem can be approached in a similar way as to that above but also includes how support can be put into practice.

- How nurses can learn to develop skills in caring communication in written text is an additional interesting research question. There is an inherent didactic potential in writing; how this can be utilised can be investigated through qualitative studies. To what extent it is experienced as positive and strengthening the caring competence, for example, is possible to examine by using a quantitative research design.
- Adopting a communication theory perspective could illuminate more clearly how information is formulated, transferred, and received. It is important to identify gaps in communication between healthcare professionals and patients, as these can lead to confusion and constitute a risk to patient safety.
- Another interesting question to study is if and how the loss of non-verbal caring communication, such as encouraging body language, a friendly tone of voice, and the like can be compensated. This could be focussed on from both a patient and a nurse perspective. It could also be evaluated in something resembling a laboratory environment, i.e. the same written expression could be tested on a group of several individuals.

Summary in Swedish

Användbarhet och betydelse av webbaserad rådgivning till patienter med hematologisk sjukdom

Patienter med hematologiska sjukdomar har rätt till stödjande vård. Stöd i form av vårdande kommunikation via webben är idag ett möjligt och angeläget alternativ tack vare både organisatorisk och teknisk utveckling. Syftet med avhandlingen var att undersöka användbarhet och betydelse av en webbaserad rådgivningstjänst till patienter med hematologiska sjukdomar. Ett utvecklingsprojekt finansierat av Svenska Cancerfonden gav möjlighet att erbjuda patienter kommunikation med en sjuksköterska via en webbaserad rådgivningstjänst. Projektet låg till grund för denna avhandling.

Fyra studier utfördes ur ett patientperspektiv. Studie I hade en tvärsnittsdesign och mätte förekomst av ångest och depression samt dessa variabelers samband med bemästring, informativt/emotionellt stöd och sömnlöshet bland patienter med hematologiska sjukdomar. Studie II var en kvalitativ innehållsanalys med fokus på förutsättningarna för att erbjuda och använda den webbaserade rådgivningstjänsten. Studie III använde en kvalitativ hermeneutisk ansats för att fokusera på patienters upplevelser av att använda rådgivningstjänsten. Studie IV var en kvalitativ deduktiv analys som undersökte hur kommunikationen inom den webbaserade rådgivningstjänsten kan vara förenlig med vårdande enligt en omvårdnadsteori.

Resultaten visade att kvinnor i 30-49 års ålder är sårbara för upplevelse av framför allt ångest. Låg känsla av bemästring och lågt stöd är associerat med ångest och/eller depression. Att själv kunna identifiera sitt behov av stöd samt uppskatta det skrivna mediet är nödvändiga förutsättningar för att den webbaserade rådgivningstjänst ska användas. Rådgivningstjänsten måste även ingå som en del av ett övergripande utbud av stödjande aktiviteter och webbaserade tjänster för att vara användbar. Resultaten visar att patienten har ett stort inflytande över kommunikationen och att den innebär en ständig tillgång till individuell medicinsk och vårdande bedömning, vilken i sig kan

innebära en känsla av säkerhet. När patienter delar sina innersta frågor och söker stöd, kan sjuksköterskan i explicita skriftliga svar ge uttryck för sin vårdande kompetens.

Följande ges som förslag på hur vårdande kan explicitgöras i skriftlig kommunikation:

- 1) Se människan bakom texten
- 2) Visa intresse och ställ frågor
- 3) Dela tonen i meddelandet, positiv eller negativ
- 4) Upprepa, bekräfta och validera/guida vidare patientens upplevelser och känslor
- 5) Uppmuntra ytterligare kontakt
- 6) Var behjälplig eller föreslå vid behov ett annat tillvägagångssätt än det patienten själv förordar

Var i vårdstrukturen en webbaserad kommunikationsmöjlighet placeras är inte självklart. Antingen som en central rådgivningstjänst eller som en kommunikationsform mellan patient och namngiven kontaktsjuksköterska. Oavsett placering finns det inte längre några praktiska hinder för att tillhandahålla antingen webbaserad rådgivning eller webbaserad kommunikation mellan patient och kontaktsjuksköterska. Tvärtom finns idag säkra tekniska och juridiska lösningar.

En slutsats är att det finns en vårdande potential i kommunikationen inom en webbaserad rådgivningstjänst. För att göra denna form av kommunikation tillgänglig bör sjuksköterskor se till att detta medium för kommunikation erbjuds patienterna. Sjuksköterskor bör också öka sina kunskaper om vårdande kommunikation i skrift och hur detta eventuellt kan påverka patienter.

En viktig fråga för fortsatt forskning är hur utbudet av webbaserade kommunikationskanaler bör organiseras. Ska sjukvården tillhandahålla centralt placerad rådgivning på kliniken, web-baserad kommunikation mellan patient och namngiven sjuksköterska (t ex kontaktsjuksköterska), och ska denna möjlighet även erbjudas anhöriga? Möjliga och viktiga kvalitativa forsk-

ningsfrågor är vad dessa olika alternativ betyder för patienter, anhöriga och sjuksköterskor. Kvantitativa forskningsfrågor kunde fokusera på resultaten av sådana möjligheter till kommunikation, förutsatt att målen för de olika alternativen är tydligt definierade. Ur ett organisatoriskt perspektiv, är frågan om resursförbrukning också intressant. Observationer kan ge svar på hur frågor behandlas och om arbetstid omfördelas. Ett ytterligare förslag på vidare forskning är att anta ett kommunikationsteoretiskt perspektiv på den skriftliga kommunikationen. Detta skulle kunna belysa tydligare hur information formuleras, överförs och tas emot. Det är viktigt att identifiera luckor i kommunikationen mellan vårdpersonal och patienter, eftersom sådana skulle kunna leda till förvirring och även utgöra ett hot mot patientsäkerheten.

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