Opportunities to Digitize Healthcare

The case of the infectious disease ward at Danderyds Sjukhus

LUDVIG HAGBERG
Opportunities to Digitize Healthcare

by

Ludvig Hagberg
Opportunities to Digitize Healthcare

Ludvig Hagberg
Abstract

This study was conducted to investigate the needs that the patients and nurses have in an infectious disease ward that can be met by digitization. A prototype was also developed as an example of a possible solution to some of these needs. The methods used for this study was observations of nurses and doctors and interviews with patients and nurses. The needs that were found were patients lacking general information about the ward, patients lacking knowledge about what would happen to them during the day, patients lacking information about their disease, lacking communication between the doctors and patients, patients having limited ways of communicating with the nurses, and care not involving both body and mind. A prototype was developed for an application that could meet some of these needs, with a focus on workforce sustainability and making the hospital stay more pleasant for the patients. The results are in line with other literature on the same topic and the needs seems to be common in healthcare. The results could probably be applied to other hospital wards as well, as they are similar to the infectious disease ward used in this study.

Key-words
Digitalization, healthcare, infection, ward, clinic, needs, patients, nurses, design, prototype
Sammanfattning

Denna studie gjordes för att utforska vilka behov som kan mötas med digitalisering som sjuksköterskor och undersköterskor samt patienter vid en infektionsklinik upplever. En prototyp utvecklades som ett exempel på hur några av dessa behov skulle kunna mötas. Metoderna som användes var observationer av läkare och sjuksköterskor samt intervjuer med undersköterskor, sjuksköterskor, och patienter. Behoven som hittades var att patienterna saknade allmän information om avdelningen, att patienterna inte visste vad som hände under dagen, att patienterna saknade information om deras sjukdom, att kommunikationen mellan doktor och patient var bristfällig, att patienterna hade begränsad möjlighet att kontakta sjuksköterskorna, samt att det saknades vård som tog hänsyn till både sinne och kropp. En applikation utvecklades med syfte att möta vissa av dessa behov, med fokus på personalens välmående och att göra sjukhusvistelsen bättre för patienterna. Resultaten av studien är i linje med annan litteratur på samma ämne och behoven verkar vara vanliga inom sjukvård. Resultaten kan också förmodligen appliceras på andra sjukhusavdelningar eftersom de är i många aspekter lika infektionsavdelningen som undersöks i denna studie.

Nyckelord

Digitalisering, sjukvård, infektion, klinik, behov, patienter, sjuksköterskor, design, prototyp
## Contents

1 **Introduction**

1.1 Purpose and Research Questions .................................................. 2

1.2 This Report in Short ........................................................................ 3

2 **Literature Study**

2.1 The Concept of Digitalization ......................................................... 5

2.2 The Current Context of HIT ............................................................ 6

2.3 The Patient Perspective ................................................................. 8

2.4 The Nurse Perspective .................................................................... 10

2.5 View on Needs ................................................................................. 13

2.6 View on Design ................................................................................. 14

3 **Method**

3.1 Case Study and Paradigm ............................................................... 17

3.2 The Case Used in This Study ......................................................... 18

3.3 Research Design .............................................................................. 18

3.4 Literature Study ............................................................................. 19

3.5 Observations .................................................................................. 20

3.6 Open Interview .............................................................................. 21

3.7 Semistructured Interviews .............................................................. 22

3.8 Method for Results and Analysis .................................................... 23

3.9 Ethics ............................................................................................. 23

3.10 My Relation to the Study ............................................................... 24

4 **Results and Analysis**

4.1 Themes from Analysis of the Interviews ......................................... 25

4.2 The patients lacking general information about the ward .............. 26

4.3 The patients lacking information about their day ...................... 30

4.4 The patients lacking information about their disease ................ 31

4.5 The limited communication with the doctors ............................. 35
**List of abbreviations**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIT</td>
<td>Healthcare Information Technology</td>
</tr>
<tr>
<td>SLL</td>
<td>Stockholms Läns Landsting</td>
</tr>
<tr>
<td>CIF</td>
<td>Clinical Innovation Fellowship</td>
</tr>
<tr>
<td>KTH</td>
<td>Royal Institute of Technology</td>
</tr>
<tr>
<td>IT</td>
<td>Information Technology</td>
</tr>
<tr>
<td>HCI</td>
<td>Human Computer Interaction</td>
</tr>
</tbody>
</table>
Chapter 1

Introduction

“... Many [patients] say this ward is a prison.”

_Nurse 5 (2017)_

As the population of Sweden is increasing and people are getting older making the need for general healthcare increase (Socialstyrelsen, 2016). As older people are more susceptible to getting infectious diseases the need for more infectious disease wards is increased both due to the increased general population as well as the increased older population (Schneider, 1983). This study will investigate how the situation for the nurses\(^1\) and patients can be improved at hospitals with a focus on digitalization, by conducting a case study at the infectious disease ward at Danderyds Sjukhus. Infectious disease wards are dedicated to treat infectious diseases, which includes diseases such as pneumonia and tuberculosis. They are important as they have the competence and facilities to keep diseases from spreading within and outside of the hospitals. Improvements in care in different areas is researched frequently but to handle the problems of staffing shortages and the increased elderly population (Centralbyrån, 2014, p.78) more research is needed. There is also a lack of research into the specific situation of infectious disease wards.

Hospitals all over the world have experienced a lot of digitalization, with HIT ranging from digital medical records to using machine learning to diagnose patients. The main focus in research done on the current large HIT systems that are used in the western healthcare has been on decreasing cost and increasing efficiency (Noffsinger and Chin, 2000; Ball et al., 2003). In general HIT makes the work of either the nurses or doctors\(^2\)

---

\(^1\)In this report the word ‘nurse’ will represent both registered nurses and assistant nurses. This is done as the needs and interactions of technology is very similar for both the groups and in the cases when there is a need to differentiate the groups, the full title of ‘registered nurse’ or ‘assistant nurse’ will be used.

\(^2\)The term ‘doctor’ will refer to all the differing levels of the doctors that are present at the ward if nothing else is specified.
CHAPTER 1. INTRODUCTION

more efficient or makes the care of the patient better (Furukawa et al., 2010; Ball et al., 2003; Abrahamsson et al., 1970) but sometimes the results are not always as expected, with more staff being needed and the costs increasing (Furukawa et al., 2010; Ball et al., 2003). The current state of the HIT at Swedish hospitals is that it is mainly focused on making the staff’s work easier, and making the care safer for the patients (Abrahamsson et al., 1970). There are, however, several areas that could be improved by adapting existing technologies and creating new ones.

Another area of research is how to improve the care and experience of the patient, both when they are in the hospital and when they are at home. A new trend is that technology is being used or developed to improve the patients’ contact with the care and make it available outside the hospital setting, by for example utilizing video chat (Linderoth, 2000). It has been investigated how to make the patients feel better about the current care that they receive, focusing on the problems experienced by the patients’ interaction with healthcare. The results are varied and ranges from the patient wanting a better dialog with the doctor, to wanting better service concerning meals and going to the bathroom (Tambrini et al., 2000). There is also a problem with the staff not understanding the patients situation, what kind of information the patient needs and wants and a lack of communication with the patient. This is not something that affects every patient doctor relationship but is a common theme in literature (Irwin and Richardson, 2006). Currently there is a lack of solutions in hospitals for fulfilling the needs of the patients even though the problems are researched in academia. Furthermore the motivations and thoughts that the staff have on both new and old technology have been analysed, showing that the staff wants the patients to have a better experience and they are willing to change to accommodate that (Timmons, 2003).

The research is lacking on the needs that correlate between nurses and patients, which also leads to a lack of solutions that help both groups. In addition, most research conducted on the needs of the groups is quantitative, that is, few qualitative studies have been made.

1.1 Purpose and Research Questions

The purpose of this report is to investigate the needs of nurses and patients at an infectious disease ward, where needs are viewed as areas that would make the situation more satisfactory for the nurses and patients. After the needs have been identified a prototype of a solution to some of the needs have been developed, to show that it is possible to solve these needs with digitalization. The following two research questions are the ones that will the main focus of this study.

RQ1: What are the current needs of the nurses and patients that can be met by digitalization?
1.2. THIS REPORT IN SHORT

**RQ2**: How could a prototype that meets some of these needs look like?

### 1.2 This Report in Short

This report will start by investigating the current literature on the subject of digitalization in healthcare and the related needs of nurses and patients. It will thus create a good understanding of the academic context that this study is set within. How the literature views the different areas investigated in this report and how I relate to these areas will also be stated. The literature study will first look into the concept of digitalization, then the current systems present in Swedish healthcare. After that the patients perspective on healthcare technology and general needs will be investigated and what the needs of the nurses are and how they view HIT. Finally I will define how I view needs and design.

After the literature review the method used for this study will be described, going into how the study has been conducted with the help of observations and interviews. To get a good understanding of how the ward works, I followed both nurses and doctors to observed the way they worked. After that interviews were conducted with both nurses and patients to get a better understanding of their situations and thoughts.

Next, the analysis of the results is presented. I will go through the themes that were discovered in the interviews and relate this to the the first research question posed in this report about the needs of the nurses and patients. The following part will go through the design of a prototype that is a proposed solution to some of the problems that were brought up in the analysis. The iterative design process to develop the prototype involve both motivations and user testing of the design.

Finally the conclusion and discussion of the results will be presented and the reports contribution will also be discussed.
Chapter 2

Literature Study

This chapter will provide the context for this study by investigating some of the previous research on HIT, in general and from the patients and staffs view. Research on the general needs of patients and nurses will also be presented. The relevant concepts to this study will be defined, both how they are used in the literature and in this study. First digitalization will be looked into, then the motivations of the current HIT systems implementation will be investigated including how these new systems affected the healthcare. After that the literature on patients’ view on needs will be reviewed followed by the nurses view and thoughts on HIT and related needs. Finally the concept of needs and how design is viewed in this study will be presented.

2.1 The Concept of Digitalization

To get a better understanding of how digitalization and the related terms are used, this section of the report will go through examples of how the terms have been used in literature and then define how they are used in this report.

The oxford dictionary defines ‘digitize’ as ‘Convert (pictures or sound) into a digital form that can be processed by a computer’ (Definition of digitize in English, 2017), which is a wide definition that mainly focuses on making data digital. Due to the inclusion of processing in the definition, one could also argue that this includes making processes digital as well. In the area of healthcare, the term digitalization is mainly used in the sense of introducing new computer systems to an organization that can handle information or tasks with the help of a computer. These systems are in articles on the area of healthcare and digitalization referred to as either ‘IT’ or ‘HIT’. The term ‘system’ is used within ‘IT’ to refers to a computer program, or several working intertwined, to achieve one or more tasks. Ball et al. (2003) uses ‘IT’ to describe the different systems that are used within healthcare to streamline processes and increase patient safety. Examples of different systems that they
discuss during their study are a system for improving communication between nurses and the pharmacy, entering medical information online and a system for looking up information on how drugs interact with each other. Other authors are more specific than only using the term ‘IT’ and instead use ‘HIT’, which means ‘IT in a healthcare setting’. Shekelle et al. (2006) and Poon et al. (2006) both reference different systems as ‘HIT’, such as electronic medical records and computerized physician order entry, which are similar systems to the previous examples.

In this study I have chosen to take a wide approach to digitization and see it as making any existing process or information digital, also including creating new information and processes through digitalization. Even though both IT and HIT refer to IT systems within healthcare, where the previous paragraph gives a few examples of such systems, I have chosen to refer to all IT within healthcare in this report as HIT to be consistent.

2.2 The Current Context of HIT

There are several areas that digitalization is currently utilized within the healthcare industry. This has mainly been done in large scale efforts to make the care safer, reduce costs, or reduce the time spent on certain tasks. Getting a better understanding of why large HIT systems have been implemented and what the effects of them have been will help create a better understanding of the motivations and effects of the current state of the HIT in hospitals. Knowing more about the current systems will be an important aspect when considering how further use of HIT could improve the situation at hospitals. This will also define part of the setting in which I will have to work in when it comes both to investigating needs and developing a prototype as both are affected by the current systems.

Efforts have been made to digitize large parts of the healthcare in hospitals all over the world. There exist many reasons for digitalizing healthcare and one can assume that not all actors think alike. By looking at the literature it is possible to get a better understanding of the motivations behind large HIT systems. Erickson et al. (2003) argues that implementing a national health infrastructure will decrease the mistakes made in the care, and provide a better way of analyzing cases where mistakes were made, but also corrected. Another aspect of the motivation for new HIT systems is presented by Ball et al. (2003). They argue that the right kind of HIT system can decrease the unnecessary activities conducted by nurses, such as administrative work, and increase quality of the care and satisfaction of the patients. They also assert that the systems will decrease cost, increase productivity and patient safety. Noffsinger and Chin (2000) claim that the Internet and new HIT systems will decrease the cost of healthcare, further providing the specific example of prescriptions as a possible area to innovate in, agreeing with the findings of Ball et al. (2003) that technology in healthcare could reduce costs. The different
2.2. THE CURRENT CONTEXT OF HIT

authors only investigate a few aspects of specific systems and therefore I would argue that their results do not directly apply to more complex HIT systems that handle several aspects of the staff’s work. As similar systems exist at Danderyds Sjukhus these articles do create a good understanding of how the current HIT systems are motivated and how the academia have argued for the implementation of said systems. The motivations are mostly aimed toward increasing the staff’s efficiency and decrease costs. This context is important to consider when looking into a new solution as it gives an indication of what the management prioritizes.

Despite the arguments presented for implementing the new HIT systems within healthcare, Furukawa et al. (2010) state that the result might not have been according to expectations. They state that the need for qualified nurses did not decrease, but rather seemed to have increased after the new systems had been implemented. The cost of care, which is usually assumed to go down, after these systems were implemented is claimed to have gone up. They conducted a big quantitative study that investigated the general effects of a general HIT system being implemented, meaning that several systems were considered as one (ibid.). The article does give a good overview on the effects of implementing large systems, but the individual parts of the systems are considered as a whole and therefore information is lacking on the effects of each individual part. Ball et al. (2003) conducts a literature review that also find negative effects in the implementation of new HIT systems. One such effect of systems to assist the nurses is that they might decrease the nurses’ satisfaction, even though it is expected that the benefits will outweigh the disadvantages in the long run (ibid.). These articles show that the effects of new HIT systems are not always as expected which needs to be considered in this study as well. One cannot always foresee what the effects of a new system is and the effects presented here compared to the expectations is a good reference for creating the prototype in this study. One reason for the systems not functioning as expected could be that the needs of the organization had not thoroughly been investigated and therefore the systems would not solve the right problems. As there seems to be a difference in the expectations and actual results of a system, there is a need of studies that contribute to creating a better base for future systems and therefore lessen the difference in expectation and result.

The aspect of how much time is spent documenting is investigated by Poissant et al. (2005) that states that the use of electronic health records increases the time that is needed for documentation done by doctors, but saw a slight decrease in the time needed by nurses. This goes against one of the arguments used to motivate the implementation of electronic medical record which is that less time is spent documenting using the new system. It is also indicated that the time increase is different for point of care documentation systems and systems where the documentation is done separate from the patients. This study is somewhat old and might not give a perfect picture of how the hospital staff spend their time today, but it gives a good indication of how the change from paper into electronic
health records changed the staff’s work. Time spent on a new technology is an important aspect to consider for the prototype that is developed in this study, especially as doctors and nurses often have a high workload.

During my literature study I came across an analysis for the needs in Stockholms Läns Landsting\textsuperscript{1} (SLL) for a large coordinated HIT system that can service the entire region. This study was done in three parts at Danderyds Sjukhus and even though I only got access to part two and three, they give a good review for the needs of the region and hospital. Abrahamsson et al. (1970) argues that a HIT system for the entire region would serve as an effective tool to plan, coordinate and control the resources that is allocated to the care. This would in turn lower the cost for the healthcare and due to SLL being such a large region with a lot of resources allocated to healthcare, even a small percentage of savings would sum up to a large total effect. They also argue for the importance of lowering costs, and that the system they propose is the only one with that justification (ibid.). The follow up article, Abrahamsson and Larsson (1971), goes into more detail of how the system is to be designed and other properties that makes the system valuable to the region such as being able to easier obtain statistics. Although the articles are old and, to my knowledge, are not about the current HIT system at Danderyds Sjukhus, they provide a valuable insight into the thinking behind the HIT systems that have been implemented in SLL. They also show that the motivations seem to be consistent with other literature, that also point out reduction in cost and increased efficiency as major motivators for new HIT. They also argue for the entire region to have the same systems, as the healthcare is publicly founded and have the same administration for the area. Having articles that comes from Danderyds Sjukhus increases that understanding of how the old systems were motivated and what management thought about them. This does benefit this study by giving a good context of what is valued and what areas are currently considered with the HIT systems.

2.3 The Patient Perspective

There are several areas where new technology can be utilized to increase the quality of care, especially when it comes to involving the patient in choices of treatment, and access to healthcare. Understanding the patient’s view of healthcare is important to understand how the care is conducted and how changes can improve the patients’ situation. The patients are the persons receiving the care and making them healthier is the primary purpose of the healthcare system and hence their needs are very important. This is a major part of this study as I aim to understand the patients’ needs. Understanding these

\textsuperscript{1}\textit{Stockholms Läns Landsting (SLL) is the greater Stockholm region’s political administration that is responsible for the healthcare in the region.}
2.3. THE PATIENT PERSPECTIVE

needs is also an important step to create a prototype that creates a positive change for the patients.

When involving the patient in decisions that concern their health there are several things to consider. Hibbard and Peters (2003) argue that the patient will not make better informed decisions when given more information but rather that it is important for the medical staff to present the information in an understandable way. Irwin and Richardson (2006) states that the amount of information and understanding that a patient wants is something that many doctors do not understand completely and often underestimate. They also claim that the communication between staff and patient involves more problems than is assumed by the staff. The above mentioned authors discuss two important aspects affecting both patient and staff. They argue from the patients’ perspective, but it is also important that the staff’s views and motivations are considered. This relates to my study by indicating that the information received by the patients is one important part of healthcare and that the doctors do not completely understand the patients’ situation and needs. It also shows that this can lead to problems in communication. These are important areas to consider when analyzing the results of this study as it points to some needs that the patient experience.

Privacy is important in healthcare and Carman and Britten (1995) argues that patients are not aware of how their medical records are used and which people have access to them. They argue that it is important to have a discussion and negotiate with the patient what is put in the electronic records as they do not have the same amount of safety and privacy as records written on paper. The article is old and one might argue that the concern for privacy has changed over time, but Caine and Hanania (2013), a more recent article, also argues that patients are concerned about what information is shared and to whom. This shows that privacy of medical information is still a relevant topic, which needs to be considered in this study when evaluating the prototype and finding the patients’ needs. Privacy is a concern that has to be considered when designing something relating to medical information as most of the said information is sensitive to the patient, and thus these concerns should also be considered in the development of the prototype in this report.

An article on the subject of patient needs is Tamburini et al. (2000). They analyze a questionnaire that is developed to assess the needs of staff and patients in a medical setting. This was done by letting cancer patients that are admitted into a hospital answer the questionnaire. The results of this evaluation were that the questionnaire was a good way of evaluating the needs of cancer patients and that there were five issues that were most prevalent needs experienced by the patients. These needs are ‘more information about my diagnosis’, ‘more information about the exams I undergo’, ‘more explanations on treatments’, ‘to have better dialog with clinicians’ and ‘better services from the hospital’ (bathrooms, meals, cleaning) (ibid.). This article gives a good indication of what needs might be the most important for any patients that are admitted to a hospital, but it is also
possible that patients with cancer have differing needs from other conditions. In any case this is a good start in evaluating the needs of the patients in this study.

Eriksson et al. (2003) conducted a meta study of patients’ dissatisfaction of hospital care where they discovered several areas that could be improved for the patient. Some of the areas are similar to the ones already mentioned, for example that the patients wanted more information. They argue that the patients want to know more about the basic information, such as who the responsible doctor and nurse are, and that they want more information about their specific treatment and medicine. It was also stated that some patients did not feel that they were able to participate in the care they were given, partly by not having any influence on what is put in their medical records. There were also patients that felt they were not given enough information about what would happen after they left the hospital (ibid.). This article analyses several different articles and seems to come to similar conclusions as the ones that Tamburini et al. (2000) suggests. As both articles identify similar areas that the patients experience problems in, it is probable that these kind of problems would occur in many wards and hospitals. It is also important to note that both articles are rather old, but as they describe problems that are of a very general nature they should still be relevant today. These authors investigate an area that is very similar to the area of my study, therefore their results can be comparable to mine.

New technology that could be used to assist patients, that have not been implemented at the ward used in this study, is another relevant research area. Stribling and Richardson (2016) is one example of using technology to improve the patients situation in a hospital. They investigate the use of tablet computer (similar to an iPad) to educate the patients on their condition and related areas. Information that was relevant to the patients was loaded into the device that was then given to the patients, which allowed the them to educate themselves on their situation. The study showed positive results on the three areas, ‘satisfaction’, ‘tablet usability’, and ‘perceived impact on learning’. The article evaluates a solution to the patients’ need for information that is found in other literature (ibid.). This is a good start in understanding how needs can be solved and also give some insight into how the patients feel about the technology. Bernhard et al. (2016) also evaluates a new technology used to increase the patient understanding of their condition. They evaluate the use of 3D models of tumors in patient’s kidneys, by 3D printing a model of the kidney and tumor and show it to the patient. This visualization of the disease increased patients’ understanding of their condition and is also a good example of how new technology is used to help patients learn.

## 2.4 The Nurse Perspective

Some of the nurses work assignments are, apart from taking care of the patient, to document treatments, administer medication, and general administrative tasks, such as prepar-
2.4. THE NURSE PERSPECTIVE

The move of a patient to another ward. These are assignments that today are supported by HIT at the ward investigated in this study. This means that the nurses interacts a lot with the current HIT systems and therefore their perspective in the relation to HIT is important to consider for a better understanding of how the current systems have affected their situation. The nurses perspective is also important to consider as the nurses are a vital group for a hospital to function. Improving their situation would hopefully also create a more sustainable working environment. This in turn could make the nurse profession more attractive and make more people wanting to become nurses and thereby reducing the current staff shortage. As this report have a focus on both patient and nurses, the nurses’ perspective is very relevant both for the identification of their needs and developing a prototype to meet some of these needs.

An’Nita and Fisher [2012] studied the nurses’ interaction with an HIT system handling the patients’ medical records. They argue that one can see the technology as a partner to the nurses using it, as the nurses were on the one hand somewhat dependent on the system while it on the other hand provided important information and support for the nurses. The system also created change for the nurses as it introduced new methods for parts of their work that previously were done in an analog way. The authors also asses that one important area when it comes to the reliance on the HIT system is that some tasks can not be solved with the help of the system. As the nurses still need to conduct these tasks, new methods that work around the limitations of the system are spawned. This is done out of necessity, as the system does not support certain tasks that needs to be done. It is also stated that the nurses are interested in finding out everything that the system has to offer and that it provides new opportunities compared to the old way of using pen and paper. During the study the nurses gave suggestions on how it could be of more help in their work, showing that they had interest in using it to its full extent.

There was some worry expressed in the study about other staff, such as managers, being able to see and evaluate the nurses’ work. This sometimes leads to irritation when other parties, mot in charge of the patient’s care, had opinions on the care without having all the information that was possessed by the nurses as they are the caregivers. This conflict was especially apparent between the administrative staff and the experienced nurses, as the nurses thought they possessed more knowledge about the care and wanted autonomy in their work (ibid.). The article used a qualitative approach to explaining how nurses interact and think about technology in an acute care unit. Although these are limitations in how the study can be applied to the ward in my study, it gives a good indication on how nurses work with technology. This also gives some understanding to how the nurses think about and handle new systems. It is shown that they like new HIT and like the opportunities they provide, but still see certain problems on how they are used. Seeing how nurses are affected and reacts to new HIT is important to consider in this study both for the needs and prototype.
An earlier mentioned article, Poissant et al. (2005), argues that there are some time savings for nurses using electronic health records. The time saved using bedside terminals equaled 24.5% decrease in overall documentation time during a shift, while when using central computers, the decrease was 23.5% compared to paper health records. One study analyzed by Poissant et al. (2005) also showed a drastic increase in documentation time when using a handheld device, equaling an 128.4% increase over using papers for documentation. This study was conducted in a home setting, so it is possible that the results are not applicable to a hospital setting. In contrast to these results Poissant et al. (2005) argues that the time spent on entering the medication and other treatment specification of the patient is increased with an average of 23.8% negating much of the time savings. They conclude that the time saved by using electronic health records does not seem to be that relevant when compared to paper based records. However, they suggest that the system, even though not visible in documentation, might come with other benefits on a system scale and that more research is needed on that perspective (ibid.). The article gives a good view on the time aspect of how nurses interact with technology, but as they themselves mention, there are more aspects to consider when evaluating a HIT system. As efficiency is claimed to be one of the major arguments for HIT these results shows that from the nurses perspective, this argument might not hold. It is important to keep that in mind when creating the prototype and investigating the needs as time is a valuable resource and minimizing the work needed to use new systems is advantageous.

Timmons (2003) investigates a case of nurses resisting the change into electronic medical records. There was no case of a nurse refusing to use the system, instead the resistance takes the form of ‘resistive compliance’, where the nurses uses the system but complain a lot about needing to do it. The critique that the nurses expressed about the new HIT system is that it does not comply with how they used to work, and that the new ways are not favorable compared to the old ones. One aspect was that now the patient records needed to be updated at a terminal, away from the patient, where earlier it was done bedside with the patient present, making it easier to ask questions. The resistance to the new system is argued to be complex and somewhat rooted in the system’s non-compliance with the old, established traditions of the nurses (ibid.). This is also a rather old study, but it gives a good view on how nurses might potentially view new technology that they do not approve of and it gives an indication of some of the problems that arose with the use of electronic medical records. It gives a context to my study and showcases some possible problems that might arise with new HIT.

There are also research that focuses on what opportunities that exists to make the situation for nurses better. I have chosen to review some of the literature on improving the nurses situation with the help of technology. Green et al. (2014) argues that using virtual reality has potential to offer ‘endless possibilities’ for educating nurses. They also state that using virtual reality in the right way provides a more immersive experience than
normal teaching and make learning more fun. Another article in the same area, Kleven (2014), investigates the potential for developing a virtual reality room for educating both healthcare staff and other groups. These articles show how new technology could be applied to help nurses and even though this area does not directly correlate with this study it gives a good indication of the opportunities for new technology in a healthcare setting.

Galinato et al. (2015), an article more in line with my study, investigates the problems and opportunities with how the communication system between patients and nurses works and how a new system could improve the communication. The study evaluates a system for communication that utilizes a digital interface for both the patients and nurses that increases the flexibility of communication, contrary to the previous button that only allowed one sort of signal to reach the nurses when a patient is in need of help. The study showed that the users were positive but saw some problems with using too much technology in a hospital setting due to the possibility of failure (ibid.). This article is very close to the area that is investigated by me when it comes to designing a prototype and therefore it provides a better understanding of what has already been done in designing solutions for a healthcare setting.

2.5 View on Needs

To understand the first research question of this report, about the needs of nurses and patients, it is first important to understand how I have viewed ‘needs’ in this study. Hence this section will go through how different scientific articles view ‘needs’ and position my view in relation to them.

One author on the subject of human needs is Abraham Maslow who strived to create a better understanding of what motivate humans. In Maslow (1943) he defines the needs of humans as a hierarchy, when certain needs are fulfilled, new needs arise. He explains this with needs belonging to different levels, where the lower levels are getting enough food and water and the higher ones include fulfilling the strongest desires that one posses. In this theory, with new needs arising after old ones are achieved, there are always some needs that motivate a person in their life. Another theory on motivation, more aimed towards how people feel about their work, is proposed by Herzberg et al. (2011). They argue that there are two types of motivations for a person in a working environment, hygiene factors and motivators. Hygiene factors are important for the employee and a lack in these factors results in less satisfaction in their work, but these factors do not provide motivation when they are increased. Motivators are factors that are not critical to the employee but when they are increased they feel more motivated. In Maslow (1943) he describes the close connection between needs and motivations and argues that the needs provides motivation for a human, this makes me argue that what Herzberg et al. (2011) describe as motivations can be called needs.
According to my view, needs are the areas in which nurses and patients see potential for improvements of their situation, as this is my interpretation of how Maslow (1943) views needs. I argue that Maslow (1943) is correct in saying that when needs are fulfilled, new needs arise and that this means that RQ1 will always be important to consider as new needs arise continually. I also believe that it is important to include the way Herzberg et al. (2011) argue about motivation, as it shows that there are two different kind of needs, hygiene factors and motivators, that exist. This emphasizes that different needs affect humans in different ways, and keeping this in mind is important for understanding what needs should be considered and how one could fulfill them, as motivators would always benefit from improvement but hygiene factors would only benefit motivations to a certain point. Therefore I have chosen to view needs as being different levels that change when some needs get fulfilled and that there are two kind of needs that have somewhat different characteristics.

2.6 View on Design

The aim of a design can differ depending on how one sees the basic concept of design and whom one chooses to design for. A hospital is a special setting as the patients are there due to illnesses, making them in many cases have a different ability to use a product than a healthy person. This is even more apparent in an infectious disease ward where most of the patients are old and some have diseases, both infectious and others such as dementia, that limit their ability to use a product. Therefore it is important to understand what my aim and thoughts are around the design made in this study.

There are two important user groups for any prototype that would be developed in the setting of this study, the patients and staff. Abras et al. (2004) argue for the importance of including the users of the prototype in the process of designing it, as it will create a better understanding of what problems the user faces.

The patients of the ward in this study are in such different positions compared to each other, depending on the diseases and age, there are also different groups within the patient group. Muller et al. (1997) argues for the importance of focusing on the possible disabilities of users and that those disabilities need to be taken into account in any design. Abascal and Nicolle (2005) is another article that also argues for the benefits of taking an approach that includes the less abled people. The design should focus on including as many people as possible as potential users, and not excluding anyone.

Another important part to consider when creating innovations for healthcare is argued by Sibthorpe et al. (2005) to be workforce sustainability, which includes three sub areas, staffing, skill and motivation. These are important as they are needed for an innovation to be accepted into an organization. This means that it is important to take the staff’s
2.6. VIEW ON DESIGN

situation into consideration when designing a product for a hospital. If this is not fulfilled, the design might not be accepted by the organization.

The approach I have taken in the design of the prototype is to make it as simple as possible to include as many users as possible. Considering the setting of my study I have chosen to approach the design as mainly benefiting a rather healthy individual as this is the user that I have access to, which somewhat goes against including everyone. Evaluating a design on very sick people is problematic in both an ethical aspect as well as a more practical one. I have chosen to also consider workforce sustainability as an important factor when designing the prototype as this will be a part of what determines the success of a potential product that could be developed from it.
Chapter 3

Method

This chapter of the report will first go through the interpretivist approach I have taken when conducting this study. Then the case that have been used for the study will be presented. After that the different methods used for data collection, interviews and observations, will be motivated and discussed. Finally the ethics of this study will be considered on the basis of the Swedish Science Council’s guidelines. The method for developing the prototype is described in the chapter ‘The Prototype’.

3.1 Case Study and Paradigm

This thesis uses the paradigm of interpretivism as it aims to describe a part of a complex system, where the parts of the system can not be separated from the whole without losing knowledge. Interpretivism is based in the belief that the phenomenon under investigation can not be explained in a purely subjective way and therefore the findings heavily depend on the researcher and the researcher’s interpretations. It is also the paradigm that is more aimed at a qualitative approach to the research (Collis and Hussey, 2009, p.56-57). This is the most fitting approach to this study as the results will not be quantifiable in numbers, but rather my interpretation of the data gathered. My subjectivism will influence the results and therefore I am researching by the interpretivism paradigm.

This thesis takes the form of a case study as it only investigates the case of the infectious disease ward. A case study is an approach used to get a more complex understanding of a phenomena than using, for example, the experiment method. It is also a good way to discover new dimensions if the researcher is open to it (Collis and Hussey, 2009, p.82-83). As this thesis uses an inductive approach and lets the result emerge from the data, a case study is a fitting methodology to use.
3.2 The Case Used in This Study

The infectious disease ward at Danderyds Sjukhus, where this study was conducted, currently consists of one old and two newly opened departments. The layout of the old department consists of several rooms that can house two persons and two rooms that can house only one person, which are used for isolation of contagious patients, or patients that are so weak that they need to be isolated to decrease the chance of contracting another disease. The two new wards consists solely of isolation rooms that can only house one patient each. The layout of the department and the rules that dictate that the patients can not leave their rooms at any time during their stay means that compared to other departments the patients and staff are a lot more separated. This also means that the patients rely a lot more on the staff as they need help completing the simplest of tasks, such as getting coffee. Many patients therefore feel like they have very little control over their situation and that the staff have a lot of power over them. This is the reason that the ward sometimes is compared to a prison by staff and patients. Apart from the aspect of isolation the infectious disease ward is similar to other wards at the hospital.

3.3 Research Design

To start of the research for this report I conducted 6 days of observations of both nurses and doctors, three days following nurses and three days following doctors, during their normal work days, following different people every time. The observations were done to get a good understanding of how the ward works and to find the best approach to take when writing this report. During my observations I saw that the most potential for improvement was in the nurses work, as they currently do have several tasks which are not assisted by HIT. The patients are an important part in the nurses work and they lack access to any IT provided by the ward, although most of them bring their phone or computer, making me also include the patients in the research questions. Choosing the patients and nurses means that I have chosen to exclude interviewing the doctors to limit the study, but having followed the doctors for three days gave me some insight into the doctor’s perspective as well although it was mainly done to get a better understanding of how the ward worked. Even if the doctors perspective was not included as a research question, the doctor’s perspective is important for the nurses work and the patients well being, so having some understanding of the doctor’s situation is good when developing a prototype for the ward. Deciding how much observing is necessary for a study is difficult and requires the researcher to decide when they believe the information gathered is enough (Blomkvist and Hallin, 2015, p.84). I decided that conducting 6 observations was enough as I learned little new in the later observations and therefore I thought it better to spend the time on interviews.
3.4 LITERATURE STUDY

When the observations were done I used them as a foundation to create interview questions for the nurses, so that I could get a better understanding of the different aspect of how they worked and their thought on technology and change. The questions were also designed to find areas where there was a need for improvement. Then 5 interviews were conducted with these questions, and in a second round with new questions, 2 more interviews were done. The new round of interviews was conducted as the first interviews indicated interesting areas where I lacked some information so the following ones focused on those areas. After the 2 interviews of round two were conducted I determined that I was satisfied with the information that I had gathered from the nurses perspective as the answers became repetitive and the new information from the second round was enough to understand the areas where I previously missed information. These interviews also were used to get a better understanding of the problems experienced by the patients, which helped with the design of the questions asked to the patients.

When all 7 interviews with the nurses were done I conducted 5 interviews with the patients to get a better understanding of their situation and possible improvements of it. These interviews were also analyzed and, together with all the other data gathered, used to identify the needs of the nurses and patients. The data was used to argue for a solution that then was analyzed to identify possible problems. One should conduct enough interviews so that the information starts to repeat itself in the later interviews (Blomkvist and Hallin, 2015, p.77-78), which is the reason why I decided to do 7 interviews with nurses and 5 interviews with patients. There is always new information that is found by conducting a new interview, but during the later interviews most of the information was repeated which made me feel satisfied with the amount of interviews that I conducted.

3.4 Literature Study

I conducted a literature study to investigate the previous research on the area of my study and to set the theoretical frame of reference. The literature study in this report was conducted mainly by searching 'Google Scholar' and 'Primo' to find appropriate articles. In the beginning of the study I also consulted with experts, mainly researchers at KTH, on what literature that could be appropriate for my research. The method of 'snowballing', looking at the references of appropriate articles to find more literature, was also used as this is a good way to compliment database searches (Wohlin, 2014). Throughout the study I complimented the literature as I gained more knowledge on my area of study.

When searching for and using the literature I have had certain limitations put on me. One of the limitations is that I have only investigated literature in English and Swedish, as these are the languages that I am proficient in. Another limitation is the access that I have to the different journals, which is limited to open source journals as well as the access granted through KTH.
3.5 Observations

To gather information about the nature of the problem, I have, as previously mentioned, conducted observations of the everyday work of both doctors and nurses. The purpose of these observations was to get a good high level understanding of how both doctors and nurses worked and identify some problems, which later was used to construct the interviews and as data for the analysis. Following the staff in their daily work creates an understanding from a different perspective than only conducting interviews. As I, in the beginning of this study, had limited knowledge of how hospitals function the observation method is a good way of getting a good understanding of how the ward functioned.

The observations were done by following a member of the staff for an entire day and changing the person followed every day. I have done three days of following doctors, from 8am to 4pm and two days of following nurses from 7am to 3pm, as well as one day following a nurse from 7am to 1pm. The selection of nurses that I followed was done by the management of the ward after my clinic contact person suggested days that were fitting. This means that there was some bias in the selection as the management might have an agenda, or a way of choosing candidates that contained some sort of bias. This bias needs to be considered in the analysis but as most nurses seemed to work in a very similar way the bias probably had only a small influence on the results. The selection of what doctor I followed was done by me showing up in the morning and then asking if someone was okay with me following them. This made the selection rather random but it still had a bias towards people willing to have me following them as well as me not following the doctors that had a lot to do that day. The reason that I did not observe patients was due to it being a rather inefficient way of collecting data. Due to the nature of a patient’s hospital stay they mostly spend their time watching TV or using their phone. Things that patients experience that are interesting to this study usually happen when the staff is in the room, which I saw during my observations of the staff. Another interesting part is how patients feel and think and to understand this interviews are more fitting.

Using observations is a good way to explore how work is done in an organization but can also consume a lot of time to get results (Blomkvist and Hallin, [2015], p.81-87). The observations can be seen as complementary empirics to the interviews as I did not conduct enough observations to be satisfied that all the data gathered was enough to answer the questions posed in this report. There is an issue with confidentiality when using observations (Blomkvist and Hallin, [2015], p.84), which is especially apparent in a hospital environment with patient confidentiality. To satisfy the confidentiality requirements, information about patients has not been included in this report and the staff that has been followed has been anonymized. As there were a lot of interactions with different people during these observations, it was not possible to inform everyone of my role. This is something that is not strictly ethical but to the largest extent possible I made sure to inform
3.6. OPEN INTERVIEW

everyone of my purpose for the observations. It was also known by most of the staff what
the purpose of my observations were as they have had other people doing similar things
as me and therefore many of them have been informed through them. The consent was
also asked for to most the people I followed, but this was a lacking aspect similar to the
information aspect as I could not ask everyone that was observed. Although I did my best
to inform as many people as possible, not everyone that could be informed was informed
as to not interfere with the work of the staff and disturbing the patients unnecessarily.
The management had also informed some of the staff as well, but it is possible that this
information was not reaching everyone and that it covered all the aspects of what I did.
It is also probable that certain people was not informed enough even when there was an
opportunity for me to do so as I had so many interactions with people and would forget
to do so at points. But within reason and to the best of my ability I tried to fulfill the
requirements of information and consent.

3.6 Open Interview

One open, or unstructured, interview was conducted with a patient, prior to the semistruc-
tured interviews, to get an overview of how technical changes could affect the patients.
This gave a good indication of the different problems that the patients face and gave a
good overview of the situation that patients find themselves in. The interview also gave a
good base for the following semistructured interviews that were conducted with 4 other
patients.

Only the theme - technical solutions in the patient rooms - for the interview was specified
and no other questions were prepared. This was done to get some indication of how the
patients view their situation, and gave a good ground to construct the semistructured in-
terviews with the patients on. As this was an interview with a patient it is extra important
with confidentiality due to the above mentioned reasons, and this was solved by making
the interviewee anonymous in the report, as well as discussing how she felt about the
information being shared during the talk about consent. Sensitive information was not
taken notes of and only general problems with the day to day operations and thoughts
about the general state of the care were written down. This patient was selected by one of
the doctors asking me if I wanted to interview a patient. This might have given some bias
as the doctor knew that the patient was willing to talk and the patient had already talked
to another student writing a thesis at the ward. As this interview was conducted to get an
indication of the patients’ problems the selection of someone willing to talk would prob-
ably affect the result in that the patient was more inclined to find problems. This could be
seen as not representing the opinions of all patients but provides, as earlier mentioned, a
good start to highlight possible problems.
3.7 Semistructured Interviews

Semistructured interviews have been used, as earlier mentioned, to get a deeper understanding of certain problems that have been identified and exploring possible solutions to these problems. As I had done previous research on the problem I had a good understanding of what questions I wanted to ask and using the semistructured approach also gave the opportunity to follow up on interesting answers.

The interviews were conducted with both nurses and patients. The selection of nurses was done by me arriving at the ward around the time between the morning and evening shift and asking if someone would be willing to have an interview. This selection is biased towards people working the day and evening shift thereby missing some representation of the night shift. This means that the conclusions made in this study might not be applicable to the night shift as it did not have enough representation in the selection of nurses. Except for this bias the selection was as random as it could be, people need to be willing to do an interview in any selection process and thus the people that had time for it should be rather random with the selection that I made. The patients were chosen by asking the nurses for patients that were relatively healthy, not having a high risk of contagion, being willing and able to talk. This is also a somewhat random selection but it does shift the selection to a group of healthy patients that are willing to talk, which might not be representative for the entire patient group. But as some of the interviewees were sicker at an earlier time that group is at least somewhat represented.

Semistructured interviews are a good way of asking questions that are targeted towards a certain subject but also allow the freedom of posing follow up questions to probe further into interesting aspects or specifying unclear answers (Blomkvist and Hallin, 2015, p.75-77). Semistructured interviews were chosen as they are a good way of getting a deeper understanding of a phenomenon that one already has some knowledge in as the main questions can be asked and interesting answers can be followed up on. The nurses were informed, prior to the interview, about the reason for the interview and what it would be used for, as well as asking for consent for this use. They were informed that they could stop at any time and that they could contact me before the final report is submitted to have their interview excluded from the report. It was also discussed how they felt about the sensitivity of the information we talked about and everyone thought that the topics were not very sensitive to them. Although this was the case they were informed that they would be anonymous to satisfy the confidentiality requirement. The patients were also informed that they were going to be anonymous in the report and could stop the interview at any time. When transcribing and analyzing data, most of the specific details of the patients’ diseases were not included to keep the patients as anonymous as possible. Missing the information about the patient’s disease could make the understanding of their situation worse, but I have chosen that the anonymization of the patient is more important in this
3.8 Method for Results and Analysis

To analyze the results of this study I have chosen to take present both the results and analysis in the same part of the report. Using this approach have the benefit of making it easier to create an argumentative text for the findings and intertwine it with analysis and literature, it is also fitting for presenting the analysis by themes. Thematization is one way of structuring the analysis, which entails dividing the analysis into different parts based on themes, and there are several ways in which these themes can be found (Blomkvist and Hallin, p.112-116). I chose thematization as it is a good fit for my research questions. First I transcribed the interviews then I tagged different themes that I found throughout them and found that the same themes were repeating in different interviews. I collected all the themes in a document and tagged what interviews that brought up each theme to be able to see the relevance of the different themes. At this point I reduced the themes and removed some that were not connected to my research questions and the ones that did not seem relevant as only one or two persons brought it up. Then the themes were further reduced by merging some of them as they were closely related or could be analyzed under the same theme. The task of finding the correct themes to use in the analysis is an iterative approach where the themes change over time as to include new thought and data (Renner and Taylor-Powell, p.3). This is also true for my analysis and the themes have changed several times throughout the analysis, both to include new thought and to get a better structure on the argumentation. The final themes are also used as the basis for developing the prototype, as described in the chapter 'Designing the Prototype'. The structure of the analysis of each theme is to include quotes to strengthen my findings and try to highlight both the direct problem as well as the underlying reason for said problem. The analysis have also been related to literature on the areas that is brought up under each theme.

3.9 Ethics

The Swedish Research Council’s code of ethics (Vetenskapsrådet, 2002) has been the basis for the ethical consideration when collecting the data. These guidelines specify four major requirements that should be considered, the information requirement, the consent...
requirement, the confidentiality requirement, and the use requirement. These requirements specify that you have to inform the participants of what you are doing and what the data will be used for, get their consent in using the data, protect sensitive information of the participants and only use the data for what is stated to the participants.

All of the information that has been gathered will only be used for the purpose of this report as to fulfill the use requirement and even though the specifics of what is investigated have changed, it is still within the area that the participants were informed about.

The interviews and observations was both conducted mostly in Swedish as this was the language that both me and the participants of this study were most comfortable in. When quotes have been used in this report they have therefore been translated into English and for the reader to get a better understanding of what they meant when seen separately, I have used brackets to change parts of the quotes to make clear what is referenced in the original quote. The quotes comes from the transcriptions of the interviews and the complete sentence of the quotes have been included in the appendix in the original language of Swedish, to be open to the reader with what was said.

### 3.10 My Relation to the Study

This thesis is made for both my master in industrial management and my master of science and engineering in computer science. I applied for this project as I saw an ad for it and it seemed to be a good fit for both computer science and industrial management, and it was within healthcare which I think is an interesting industry. I have very little experience of hospitals, I have never spent the night in one, and that made the project more interesting for me as I have very little knowledge about the area and like to learn new things. This also meant that I was less influenced by the preconceptions that someone with more previous experience on the subject might be.

The project was created by the Clinical Innovation Fellowship (CIF), a group with the stated purpose of improving healthcare world wide. The team I work with is looking into all kind of improvements for the infectious disease ward. There are five other students doing four master theses under the same group with different focuses. They are looking into the turnover of nurses, competence follow up, communication between the staff, and solutions to relieve some of the isolation the patients feel at the ward. During this study the interaction with the students that investigates areas close to mine was kept to a minimum as to avoid plagiarism and other ethical issues.
Chapter 4

Results and Analysis

As mentioned in the method chapter, I have chosen to present the empirics together with the analysis. This chapter will first present the themes that were achieved by thematizing the interviews and how they were grouped and filtered then the different themes will be presented and analyzed.

4.1 Themes from Analysis of the Interviews

The interviews were analyzed by thematization, which was done by going through all the transcriptions of the interviews and tagging themes that were found. I have also been relating the themes to the present literature on the different relevant areas to see that they are within the current context of conducted research. As the first research question is about finding needs that can be met by digitalization I chose to only analyze the themes that fit the question. After the thematization was done I discovered that there were several themes that were not a good fit for the research question, by either not being a need or not related to digitalization, examples of such a theme would be the lack of resources or the staff shortage.

One theme that was discovered during the analysis was the distribution of medication to the patients, this is a time consuming task that currently involves finding the right medicine, checking it of in a binder, and then check it of in the computer. This was brought up as a problem as it took time and, although an interesting task during the first time as a nurse, it quickly became mundane and added no tangible value to the work. It was suggested that there exist machines in other hospitals that can provide a faster way for the nurses to get the medication that needs to be distributed. Due to the already established solution to the problem, for example [The Future in Automatic Medicine Distribution](2017), and since this problem mainly affects the nurses and only affects the patient indirectly, I have chosen to not discuss it any further even though it is a theme that fits the research
The themes that were both needs for the nurses and patients and are related to digitalization were mainly related to information and communication. The final themes that will be presented in this chapter are: patients lacking general information about the ward, patients lacking knowledge about what would happen to them during the day, patients lacking information about their disease, lacking communication with the doctor, lacking communication with the nurses, and having care involving both body and mind. As many of the themes are similar, the analysis will sometimes go in the same directions in the different sections, therefore some discussion that affects several themes will only be presented in depth in one of the themes.

4.2 The patients lacking general information about the ward

“So I can not walk around out there?”

Patient 3 (2017)

The quote was said by a patient during an interview as I asked if she felt isolated as she could not leave her room. The reason for her not knowing was most likely not that she had not been told, as the other interviewed patients all knew it, but rather that she was told at a time when she had problems comprehending the information. This is further supported by Patient 2 (2017) saying

“It probably took more than a day before I knew I was at an infectious ward, first I believed I was at the general medicine ward.”

The patient said that when she arrived she was very sick and could therefore not comprehend what was happening to her and what the staff was saying during this time. There are also problems with the staff assuming that the patients receive and understand the information the first day at the ward, and if this is not the case the patient might never learn the information. When asked about the how the patients are informed about how things work at the ward Nurse 6 (2017) answered

“when the patient arrives that information should be given and if the patient has been here a few days, one assumes that the information has been given, but that is not always the case.”
4.2. THE PATIENTS LACKING GENERAL INFORMATION ABOUT THE WARD

This indicates that this problem is noticed by the staff as well, and could result in the patients ending up in uncomfortable situations such as as

“When they enter the corridor they sometimes almost get yelled at.”

Nurse 6 (2017)

The current general information that the patient receives is, as shown, limited and it has unwanted effects. One also have to consider that the reason for the patients’ isolation is due to the risk of contagious diseases spreading, which could result in a lot more serious problems than the patients feeling uncomfortable. Most of the diseases at the ward is not very dangerous even if the patient leaves the room, as they have a low or even no chance of spreading at all, but for the highly infectious and dangerous diseases, such as tuberculosis, serious problems, such as unnecessary suffering and even death, could result from patients leaving their rooms and spreading the disease. The examples that I brought up are mainly focused on the specifics of the infectious disease ward and not on more general things that might be advantageous to know for the patient, such as knowing why the nurses use gloves when touching the patients. The reason for this is mainly that the information about why they are isolated and how they should behave in the context of isolation is one of the most important pieces of information that the patient needs to behave correctly when spending time at the ward. Not receiving this information is an indicator that other information is missing as well. It can be argued that this information is not necessary for the patient to become healthy, but I would argue that the patient will have a better time knowing more about their situation and this might alleviate some of the feeling of being in a prison. This would in turn relieve some of the stress that is felt by the patient, which does decrease the severity of some infectious diseases (Cohen et al., 1999; Leserman et al., 1999). As the patient needs a lot of information, much of which is more important than the general information talked about here, such as information about the disease and treatment as this affect the patient more directly, it is also the case that with the limited time the staff have with the patient this information is left out. When asked, the patients also expressed that they had no control over their situation at the ward, which I think is very natural due to the environment of isolated rooms and the knowledge gap between patients and staff. Although giving more general information to the patients would not remove this feeling it might reduce it as the patient would have more knowledge about what was happening and why.

The advantages of giving the patients more general information is not only good for the patients, the nurses expressed during the interviews that when the patients were calm and content their job got easier. If the patients have more information about their position they would have a better understanding of what is happening and would therefore, according to several of the interviewed nurses, be calmer.
CHAPTER 4. RESULTS AND ANALYSIS

It is important to consider why the current situation is as it is at the ward, why the staff do not satisfy the patients’ need for information even if it would make the staff’s situation better as well. As mentioned, the information is assumed to be given when the patient arrives and the nurses assume that this information is understood and remembered by the patients. This points to the staff having faulty assumptions of the patients’ situation, which could be due to a number of reasons. The situations that the staff and patient find themselves in in a hospital are very different, with the nurses and doctors seeing most patients’ diseases as nothing special due to them treating similar cases every day, and the patients which sometimes experience the toughest times of their life. This is something that the staff is aware of as it was brought up during the nurse interviews, but it was also clear that they saw most diseases as routine. During my interviews with the patients there was a big difference in the feeling that different patients had about their situation. Most of the patients that only had an infectious disease seemed relatively okay for their situation. What seemed to be a bigger issue was when patients had several diseases that affected the way that they could live their life, both what ability they would have to take care of themselves and the possibility of a bad outcome. During my observations I even heard a nurse say that one of the best educations for a nurse is to become a patient, as they would see the situation that they face. The different situations of staff and patient are something that affects most of the themes that are brought up in this analysis as it creates a divide between the two groups, which in turn creates problems. When working with humans it is hard to judge what the other person needs and wants and the position that staff and patients find themselves in, with widely differing views of their stay and interactions, makes understanding each other even harder. Providing general information about the ward is also affected by this as the staff working according to routine can not understand that the patient needs information about their current position to get a better understanding of how they are affected by their disease.

Another problem is that the nurses and doctors know a lot about the patients’ situation and assume that the patients possess knowledge that they do not. This was something that I experienced as well when I was observing both doctors and nurses. They assumed that I knew what they were talking about at most times and that I knew the different procedures at the ward. Sometimes they explained what they were doing when I already understood it, and sometimes they did not explain something that I did not know. An area that also has this problem is teaching where Kalman and Jane (2009) assert that an expert in math has problems comprehending how to present information to a student as they are in a different position, with the teacher knowing a lot more than the student. Part of the problem is also that it was a long time ago that the teacher was in a position on the subject where they needed to learn the basics and they have therefore forgot how it was to be in that position (ibid.). This shows that the issue is not isolated to healthcare but other areas also suffer from problems with transferring knowledge, even when that is their primary
4.2. THE PATIENTS LACKING GENERAL INFORMATION ABOUT THE WARD

The nurses also need to prioritize their tasks as they have limited time in a given day and staffing shortages are common in Swedish hospitals (Centralbyrån, 2014, p.78). Nurse 6 (2017) described a nurse’s day as being chaos and just trying to get by and keep the patients alive and then handing over the chaos to the next shift. This was an exaggeration according to the nurse but it shows that everything can’t be controlled and that one has to prioritize what is important and realize that everything can’t be done for the patients. The basic task of all the staff in a hospital is to keep the patients alive and treat their illnesses, which is much more important than giving more information to the patients, making it so that the available time is spent on giving medications or helping someone go to the bathroom. Berg and Danielson (2007, p.504-505) argues that one of the most important parts of the patient nurse relationship is fostering a caring relationship as this gains the patient’s trust. Part of this is understanding the patient’s entire situation, such as what they liked and how many children they had, as well as having a positive attitude even when stressed. One of the aspects to why a caring relationship is not achieved between the nurse and patient was the lack of time that the nurses had with the patients (ibid.). The caring relationship to the patients is something that was brought up by several nurses as something that they thought important, with one nurse learning all the patients favorite team in football to create more trust. The problem of lacking time is, as previously mentioned, also present at the ward and considering that a caring relationship is considered important by both patients and staff, giving general information about the ward is even lower prioritized. It is easy to understand that the physical health of the patient is prioritized over creating a better relationship with the patient, and that in turn is prioritized over giving the patients more information about the general situation at the ward, but giving this information is an important part in the well-being of the patients.

With a lack of resources and staff, implementing a routine for this could be problematic but would provide benefits, such as the earlier mentioned ones of less stress for the patient, better safety, and a better working situation for the nurses. The basic idea of giving more information to the patient about their situation is simple and might sound as if it should not be a priority when other more pressing issues exist within Swedish healthcare. Even though this is the case I argue that the simpleness of the problem is something that is one of its strongest points as a simple solution could provide a much better patient experience, given the information above. Technology has a lot of potential to solve this problem as it does not get affected from doing a similar task several times, and thereby forgetting to give out certain information. It is also preferable to find a solution that does not increase the workload for the staff and that is something that could be done with digitalization. It has been proven that if the patients are provided with the right tools to obtain information about their situation in a medical setting they make use of them to become the more informed (Stribling and Richardson, 2016).
4.3 The patients lacking information about their day

“You get breakfast in the morning and lunch and dinner, then you should sleep”

Patient 4 (2017)

This was what a patient answered when I asked if he knew how his day looked like. Of course there is a more nuanced picture of the knowledge that patients have about what will happen to them during a normal day, but the patients said that they received no information from the staff about how their day would look like. This resulted in that the longer a patient was at the ward, the more they knew what would happen as they remembered how the previous days looked like, but this took a few days to learn and in the beginning this was something that none of the patients knew. Some of the patients said that they did not see the information about how their day would be as very important, most of them valued other information higher, such as information about their disease. Even though the patients did not value that information highly it did cause problems for them such as not knowing when the doctor is coming, and thereby not being able to prepare themselves. The view on how their day is was similar to how the patients felt about the general information about the ward and their situation, that it is not necessary, but some thinking it would be nice to have. Another aspect, as brought up earlier and stated by several nurses, is that the patients are calmer when having more information about their situation, thereby making the nurses’ working situation better. It is important to note that even the staff do not have the detailed information about how the patients day will look, partly due to the nature of healthcare where emergencies are common, and therefore the schedule can change with little notice. What the staff know is more general, such as tests being conducted on the patients in the morning and the doctors are meeting the patients before lunch, which I argue is enough information to provide to the patient to alleviate some of the need for more information about their day.

The patients’ knowledge about their day is in many aspects similar to the patients’ lack of general information about the ward, which is why I will focus on the areas that I believe differ and only briefly mention the ones that are the same. As the doctors mainly have the medical responsibility for the patients and the nurses do everything else for the patients, the responsibility of providing this information would fall on the nurses. They have a lot of tasks that they need to do during a day and therefore have to prioritize what they spend their time on. The problem of not having time for the task is the same as for providing the general information about the ward, as is analyzed in a previous part, and the same issues apply to giving the patients information about their day. The reason for the patients not receiving information about their day could also be in part due to the staff thinking that
The information is not important to provide for the patient as it does not affect the staff’s work much. During the interviews with both patients and nurses it was expressed that the patients were usually okay with staff entering the room for talking or testing. As earlier mentioned, the patients do not value the information that much and therefore do not ask for it from the staff. These reasons cause the staff to not realize the negative effects that the patient’s lack of information about their day have.

As many patients feel as if they are in a prison the general feeling could be improved by giving them more information. It is understandable that the primary priority is not to inform the patient of how their day will look like but rather to do the necessary medical treatments to make the patient better physically. Therefore this need is not prioritized within healthcare including the ward investigated in this study. A technical solution that would not increase the work of the staff but still provide the patient with information about their day would be adventitious. I see this information not as a necessity for the patient, but rather a part in making their stay more comfortable. As earlier mentioned, this is also something that is seen as important for the nurses as content and calm patients would call them less and create a better atmosphere at the ward. Another benefit would be that the patients could prepare for the doctors visit and the test taking and thereby making the staff’s work even easier.

4.4 The patients lacking information about their disease

“... One needs to ask and then you get an answer, but if one does not ask one does not receive an answer.”

Patient 5 (2017)

This quote describes how most patients felt about the information they received about their disease. The information that patients are given without asking further questions is very basic and the patients did not believe that they received enough information without asking. During all patient interviews it was clear that the patients prioritized getting information about their disease and how it affected them over all other information. They did however believe that if they asked for more information they did receive it, and if for example the nurses were asked about things that only the doctors could answer, the nurses relayed the questions to the doctors. Although the staff was open to answering questions by the patients, it should be noted that sometimes information is needed, to know what questions to ask. If the staff do not provide enough information about the patient’s disease it could result in the patient not knowing what to ask and therefore not receiving the information that they need or want. I believe it to be important that the staff provides patients with the knowledge that they want and need about their disease.
without the patients asking. Patients not receiving enough information about their disease and what the different test results show a problem with healthcare throughout the world. One example of the patients lack of information is Reynolds (1978) that conducted several interviews with patients in an UK hospital. He argues that the patients want all information, even if it is bad. Many of the patients in the study did not receive adequate information about the tests that were conducted on them and this lead to more anxiety for the patients in certain cases. If the results from a test show that nothing is wrong with the patient and the patient is not told this, the anxiety experienced is unnecessary. One negative aspect of having high anxiety is that it leads to more narcotic drugs being administered (1978, p.1675-1676). Jenkins et al. (2001) conducted a survey of 2331 cancer patients in the UK to see what kind of information that they want. The results showed that 87%

There is also a big knowledge gap between the staff and patients as both nurses, and especially doctors, have a long education in medicine and care, meaning that the communication between the staff and patients can be problematic as the two groups can interpret and understand information differently. Doctors might for example sometimes use medical jargon that is not understood by the patient. This is supported by the previously mentioned article Reynolds (1978) where certain patients are unsatisfied with the way that the doctors do not involve the patients in discussions about their situation. One patient mentioned that the doctors sometimes stand at the end of the bed talking to each other using medical jargon that the patient did not understand and thus making the patient feel excluded (1978, p.1674-1675). The article is old but as it is on the same topic as my study and similar issues are found, therefore I still find it relevant. Another article that presents a similar problem is McCarthy et al. (2012) that by conducting a study on patients’ ability to recall information from a doctors’ visit found that patients with better knowledge of medicine could better recall the information given by the doctor. This indicates that the communication was on the wrong level for some patients to understand it.

The way that the doctors communicated with the patients in my study was different according to different patients, which could be due to the patients having different doctors or having a different knowledge of medicine. Patient 2 (2017) believed that the doctors used unnecessarily complicated words to communicate information and that this was especially apparent for the older doctors. However, most of the other patients believed that the doctors talked at a level that they understood, and they were satisfied with the communication in that regard. As the patients disagree on how well they can understand the information the doctors give them, it might be that the knowledge gap between patients and doctors mostly cause no problems at the ward. Considering that I have a small sample of patients, I do however believe that even the small indication of a problem is worthy of further investigation, especially as this is an area where other literature has found issues.
4.4. THE PATIENTS LACKING INFORMATION ABOUT THEIR DISEASE

There are also differences between patients of how much information they want. Patient 5 (2017), an interview with a patient and a close friend with responsibility of his care, asked for an extra meeting with the doctors as they wanted to know more about how they will be affected by the disease. Patient 4 (2017) on the other hand thought that he had all the information that he needed and that the time spent with the doctors was enough. But he was in a situation where he had previously received a lot of information about his condition and was a repeat visitor to the ward. This is a rather different position compared to most other patients and therefore I would say that his opinion does not reflect the opinions of patients that do not have to visit hospitals regularly, and it is probable that his opinions do not reflect on the opinions of all the patient that repeatedly visit the hospital either.

What most patients were in agreement on was that they wanted to know how the disease would affect them personally rather than getting general information about the disease. Research on the area of what information different patients want shows that there are some differences depending on the patient. Leydon et al. (2000) investigates cancer patients’ attitudes towards information and concludes that different patients want different information. Some cancer patients did not seek out more information than the one given by the staff, while others wanted all available information about the disease, but it was agreed by all patients that they wanted the general information about their disease. There was also a difference in want for information for the same patient, depending on the time since their diagnosis. Both the kind and amount of information that a patient wanted change over time, differing both between patients and what condition they were in. Finally Leydon et al., 2000, p.913 concludes that the way that patients want information is complex and that there are several factors that decide what information a patient wants.

Cancer is an area where diagnosis and treatment have life altering consequences and as such it differs some from infectious diseases, that usually are treatable and the patient is able to make a full recovery, but it is still applicable that different people have different needs on information. Another study, Faden et al. (1981), conducted on patients and doctors concerning epileptic seizures found that the patients did not want any information withheld and this stands in contrast to the previous author arguing for some people not wanting all information. With this information as well as the results from my interviews I would argue that the patients should be given so much information that they are satisfied. The amount of information could differ for different patients but there should be a way for patients to receive more information if they want to without having to ask the doctor for every piece of information.

During the interviews with the nurses it was said that the information about patients’ diseases can only be provided by the doctors. Nurse 6 (2017) said that the nurses could only provide very basic information that they were certain was correct and that did not alter the patients’ life in a major way, such as them having cancer. The example Nurse 6 (2017) used to explain what information could be provided by the nurse was that the
CHAPTER 4. RESULTS AND ANALYSIS

patient received antibiotics that ate the disease, which gives a good indication of the level of information they can provide. As the nurses can not provide this information, the task of providing the patients with adequate information about the disease falls on the doctors and therefore the next paragraph will mainly focus on the patient doctor relationship in regards to information the patient about their disease.

One aspect to why the patients do not receive enough information about their disease is due to the staff not understanding which amount and what kind of information the patients want. While the patients that were interviewed had different views on the information they received by the doctors, almost all patients had in common that they wanted more information about their disease. Some of the doctors, on the other hand, believed that the patients did not have use for any more information than they received, although some doctors agreed that the patients did not receive enough information. There exists previous studies on doctors and patients having different views on what information is important for them, showing that this is an issue in other hospitals as well. Irwin and Richardson (2006) claims that doctors do not understand the amount and kind of information that patients want about their disease. Another study on the same subject is Faden et al. (1981) who investigated what information the patients receive and how they feel about it in epileptic seizure care. They state that the patients want more information and that doctors mostly think that the general information about the patient’s disease is needed, as well as the major risks associated with treatment options. The patients, on the other hand, wanted to know much more about risks and alternative treatments and did not want any information withheld from them, even if it was anxiety inducing. They conclude that the difference in how doctors and patients see what information is necessary comes down to different assumptions about the patient doctor relationship (1981, p. 732-733). I agree that the patients and doctors seem to have different assumptions of how their relationship should be, even though their views are rather similar.

Another obstacle to doctors informing the patients more might be the time and effort this requires. However, giving the patients information should be something to prioritize. During my observations I heard several doctors saying they were against the patients having access to their medical records as the information would not be usable for them while it would only cause more work for the doctors. They thought that if patients wanted more information they could just ask for it. Some doctors were more positive though, as they saw the benefits that access to the medical records would provide for the patients. This shows a divide in how different doctors consider the communication with patients, some believing that patients need more information, some believing they have enough and can ask if they want more. With the doctors being open to provide more information when requested and the patients wanting more information it seems as if this would not result in a problem between the two parties. However I would argue that problems arise due to the patients having to ask questions to be provided with more information as this
4.5. THE LIMITED COMMUNICATION WITH THE DOCTORS

makes them feel like more of a liability. Some patients were even hesitant to call the nurses to get more coffee as they though nurses had more important tasks to attend to. This might translate to patients not wanting to ask the doctors for more information as this would make them take away time that the doctor could spend on something `more important'. From this problems could arise with patients not getting enough information about their disease.

The problem of patients not having enough information about their disease could be solved by digitalizing the processes used to inform them. The primary way that the patient receives information today is by talking to the doctors, and this process could be supplemented with digital tools to give the patient more options to inform themselves. This has already been investigated by using digital tools to let the patients inform themselves and it showed positive results of the patient feeling more informed about their medical condition Stribling and Richardson (2016). Furthermore the benefits of a patient understanding their health situation are many, such as higher trust in their doctor, an increase in motivation to follow the treatment plan and increased patient satisfaction Tang and Newcomb (1998).

... The time they meet the patient is a bit like a bad father that spends quality time with his son and wants to do as much as possible during that time. 

Nurse 6 (2017)

Under normal circumstances the doctor visits a patient one time per day in the morning, for around 5 to 10 minutes. The quote is a reflection from a nurse on how the doctors spend their time with the patients, trying to inform the patient about everything that has happened as well as asking the patient about new information. As so little time is spent with the patient and so much information needs to be communicated, the patient does not always feel that the time spent with the doctor is adequate. Nurse 6 (2017) also said

"I know many patients that forget to say [certain] things to the doctor."

As the doctors come in unannounced and stay for only a short time, it is hard to for the patient to remember everything they want to say at that time. This is a problem somewhat connected to the patient knowing very little about their day and therefore not being prepared for the doctor coming. Patient 5 (2017) was, as earlier mentioned, an interview with the patient and a close friend and they were also concerned about not being
able to contact the doctors in a good way. The friend needed to take a lot of responsibility in taking care of the patient, both at home and in the hospital, due to a disability and the doctors did very little to facilitate this situation. They only did their morning rounds and when the friend wanted more information she had to ask for an extra meeting with the doctors. This meeting happened in the middle of my interview with them and it was a bit surprising as no one of us knew it was supposed to happen at that particular point, showing the lack of communication between doctor and patient. To get the extra meeting the friend had to make a lot of calls to the ward to plan it, and she thought it was very unnecessary as she should be able to write to them what times she intended to be at the ward and the doctors could adapt to that. Both the patient and friend also had problems with remembering everything that they wanted to ask the doctors as it was forgotten when the doctors arrived. She thought a simple solution to that would be to have a pen and paper in the room where questions and thought could be written down for the doctors to read when visiting in the morning.

So the main problem experienced by the patients seems to be that the doctors only visit unannounced for a short moment and there being no other simple way of contacting them. I have, as earlier explained, not investigated the doctors’ view on this in depth but Irwin and Richardson (2006) suggests that this is a problem that is not clearly seen by the doctors as they have another view on what kind of information the patient needs. As information is closely related to communication, I argue that doctors see less need for communication as they think the patients want less information than the patients actually want. When it comes to the communication with the staff Tamburini et al., 2000, p.33-36 argues that the patients want ‘to have better dialog with clinicians’, which further supports the findings on patients wanting better communication with the doctors. As the communication between doctor and patient mainly concerns information about the patient’s health situation and disease this is closely related to the previous chapter about patients wanting more information about their disease.

There are also some problems with communication between different wards, especially ones at different hospitals, which was expressed by both Patient 4 (2017) and Patient 2 (2017). Patient 4 (2017) had been to other hospitals treating the same disease and he said that the communication between the different hospitals was lacking and that he had to repeat a lot of information every time he came to a new ward. He said that this was mainly due to the hospitals sometimes using different HIT systems for medical records and therefore not being able to transfer information between each other. Patient 2 (2017) had been to a different ward where she was still admitted and when she was considered well enough to leave the infectious disease ward she had problems leaving as the communication with the other ward was lacking. Both these patients are good examples of lacking communication in hospitals. As both patients were having problems with medical conditions, this communication fall upon the doctors due to them having the responsibility for the medi-
4.5. THE LIMITED COMMUNICATION WITH THE DOCTORS

cal condition of the patients. Patient 2 (2017) even expressed that she thought it might be sufficient if she would receive an email from the doctors of the other ward, about what her status was at that ward so that she would know what would happen to her when she was done at the infectious disease ward. She was left without any information and the doctors at the infectious disease ward were the ones that had to find out what was happening and how to proceed. Kripalani et al. (2007) investigates the communication between in-hospital doctors and the primary care doctors through an analysis of observational studies. They find that the communication is lacking and are often incomplete or delayed to such an degree that the doctor doing follow up on a patient does not have the information from the first doctor visit. The communication between doctors is argued to have changed, as before only one doctor took care of a patient, but with the increase of several doctors being involved treating the same patient, the importance of communication has increased. Other factors that are important for the communication to work is to use some sort of a system, digital or otherwise, as this is currently lacking (2007, p.838-839). Reed and Stanley (2003) evaluates a new system for older people moving from a hospital to a care home where the purpose of the system is to make the move easier and create continuity in the care. The results were mainly positive from both the staff and elderly and was considered to create a more patient centered care (ibid.). These articles provide examples that the communication is lacking when several doctors or care units are involved and that it is possible to improve the communication with the implementation of a system. This is an area that have a lot of issues and during my observations of the doctors it was apparent that they thought communication between hospitals and between doctors was a major issue in their daily work.

It should also be mentioned that the different expectations of the doctors and the patients when it comes to how much information about the patients disease should be communication is present in the area of patient doctor communication. It is an very important issue but as this was discussed in the previous chapter about patients wanting more information about their disease, it will not be repeated in this chapter.

To understand patient doctor communication one has to understand how the doctors view the patients. According to my observations the focus of the doctors was on how the disease could be treated and they take pride in their knowledge in medicine and ability to cure patients, where most of the nurses takes pride in the patients feeling good during their stay. Several times during my observations I commented that the work of a doctor is very similar to that of a computer engineer, where there is a problem and you test solutions and see if it works, and many doctors agreed that it was true to a certain extent. Some doctors, on the other hand, did not like the comparison and believed that medicine was different in that one have a lot more restrictions of what can be done to a patient in comparison to a machine as they are human. Many of the doctors also believed that more complications arose when you dealt with patients as humans are more complicated
in their communication than machines. I seemed as if the doctors take the approach that
the communication between the patient and doctor is a hindrance which would explain
parts of why there exist problems in this area. At another point one doctor commented
that it was important to meet the patients every day, or at least when they arrive at the
ward, as this makes them more human, but still it happened that some doctors did not
take the time to visit all patients. One day I followed a doctor that did not have time to
have lunch, indicating that their work is stressful. This might be one of the reasons for
the lack of patient contact, but it is probable that several other factors plays a role as well.

During my observations of the doctors it was apparent that different doctors approached
their work somewhat differently. One team of two doctors chose to split up and visit
half the patients each and another team of two doctors visited all the patients together.
Even though several aspects of the communication with the patient was standardized,
such as when it should happen and what should be brought up, the doctors still have a lot
of freedom in how to conduct the meetings. This coupled with the different personalities
and ways of talking of the doctors, makes it so that the patients have different experiences
of the meetings. This issue makes the analysis of the communication between doctors
and patients more complex as communication can be very different between different
doctors and patients. The issue is not as noteworthy when it comes to the patient nurse
relationship as nurses have a more standardized way of interacting with the patients,
although the personalities of course still matter.

To solve the issue of the communication between patients and doctors, one must both
consider the practical aspects of how the communication can be done and how this com-
munication is considered by both parties. Finding a solution such as utilizing a chat, email,
or even pen and paper is simple, but using the method and understanding what the differ-
ent parties expect of the communication is more complicated. Understanding the problem
and solving it will require more research than done in this master thesis, but at least I can
shed some light on the issue.

4.6 The limited ways of communicating with the nurses

“...Whether one really needs help or just a cup of tea, it is the same button”

Patient 5 (2017)

This is how one patient describes the problem of only having one button to call the nurses,
for whatever the patients need. Some patients thought that it was rather stressful to only
have one button to call the nurses as that would take time from the nurses that might be
better used elsewhere. This sometimes lead to patients not wanting to call the nurses for
4.6. THE LIMITED WAYS OF COMMUNICATING WITH THE NURSES

certain things as they were not considered important enough. Having only one button without priority was something that both Nurse 5 (2017) and Nurse 6 (2017) pointed out as a problem for the nurses as well, they both thought that it would be good to have more than one button so that the calls could be prioritized when there was a lot to do. This is one problem that affects both patients and nurses as it brings stress to both parties that could be avoided with another system. It also makes the patient be very dependent on the nurses as they need to trust that they come when needed. Having another system could make the patient feel more trust in the nurses to come quickly when necessary as they then could prioritize the calls. Nurse 6 (2017) also pointed out that the system sometimes failed as the button could disconnect from the wall when the patient is moved or that the nurse accidentally pulls it out during a patient visit. Having a system that fails in a hospital setting could be very problematic for both the patients trust in the staff and care as well as a direct danger in that the patient might not be able to communicate an emergency. Trust is important for both patients and nurses to decrease the patient’s feeling of vulnerability and maintain dignity for the patient (Berg and Danielson, 2007, p.504-505). I acknowledge that the issue of how the nurse is contacted will only give the patient slightly more trust in the nurses but a small increase is nonetheless important for the wellbeing of the patients. In contrast to some patients feeling that the communication with the doctors was lacking, I found that all the patients thought that the communication with the nurses was good, meaning that they interacted with the nurses enough and that the concerns they had could be brought up with them, even though the way of calling them resulted in some issues.

Another issue that affects the patients’ use of the red button to call the nurses is the nurse-patient relationship. Most of the patient had some issue with the fact that the nurses worked in three different shifts during the day and that there was different nurses that took care of the same patient frequently. This lead to the patients not feeling as if they knew the nurses on a personal level which in turn made it harder for them to understand how calling for the nurses was viewed by the different nurses. All of the nurses that I interacted with were very understanding of the patients calling them for small things, as they knew that the patients are dependent on them. This was, however, not understood by all the patients. In general a good caring relationship is something that is strived for both by the patients and nurses but lack of time that nurses spend with the patient is a frequent problem to foster this relationship (Berg and Danielson, 2007, p.504-505).

There could be many underlying causes to why there are problems with the way the patients contact the nurses. When a system is implemented it takes a lot of effort and resources to change it and that could be a reason why it has not changed. Many of the nurses also believe that the red button is good enough, reducing the will to change within the staff. As with many of the issues that concerns the patients there is an underlying problem with healthcare as the patients have very little power. So a new system would
might be beneficial to the patients but still not implemented as the patients can not push for it due to them lacking power to do so. When doing my observations at the ward I noticed that the doctors mainly focused on treating the diseases and not very much on how the patient felt in general. One example of this was when the doctors did not take the time everyday to visit all the patients, even when making a comment that the doctor’s work became better when doing so. The doctors are a group that have a lot of power at the ward which is exemplified with the upper management once coming by the ward and to my knowledge only talking to doctors during the visit. The infectious disease ward was considered to be less hierarchical than other wards by all of the nurses, but some of them said that this did not change that the fact that the ward still had a strong hierarchy.

With this problem mainly affecting the nurses, at the bottom of the hierarchy, and the patients who are also in a very low power position, the issue is not given a high priority. Recently a lack of staff has affected the infectious disease ward and they have had to close down some beds. This has lately been the main focus of the management which further decreases the priority of implementing new HIT.

Another problem that the nurses pointed was that several patients do not know Swedish or English, making it hard to communicate with them. To communicate with these patients the staff had to call for an interpreter, which presented a large problem. The interpreter could not be present all the time and therefore the communication with the nurses was not always possible. As healthcare in general is very dependent on communication to solve the patient’s problems, language barriers could be very problematic for both parties. This was brought up both during my observations and the interviews with the nurses and could be considered a major problem. Some of the everyday consequences, that I experienced, was that choosing food was very hard, but it also could result in more serious problems with the patient not being able to describe how they feel and what they need help with. With patients knowing Swedish being hesitant to call for the nurses for help, I could only imagine that it would be even worse for patients that can not talk the same language as the nurses. Due to me only knowing English and Swedish I could not interview these patients, but it would nonetheless be an interesting topic to investigate further.

Currently mostly the older generations are housed at the ward and many of them have several illnesses that decreases their ability to communicate. In general this could make it hard to find a solution that fits, as older people are less used to technology and with other illnesses, they might have decreased motor function or other impediments that would make it hard for them to use technology. A technical solution for patient nurse communication would need to take these problems into account. However, as the usage of technology is increasing even in the older generations, the problem of patients not being used to technology should decrease with time.

In the future, patient nurse communication at the ward can be improved by having sys-
4.7. CARE INVOLVING BOTH BODY AND MIND

tems similar to the ones used in other parts of society, with instant messaging, email, phone calls and more. The ward not using such systems, or systems that fill the function of communicating without face to face contact, severely limits the flexibility of the patient nurse communication.

4.7 Care Involving Both Body and Mind

“It [the care] is very divided and they should have one entirety, one unit, one should treat the entire human.”

Nurse 4 (2017)

During one of the interviews with the nurses this quote came up when the nurse described that she thought there was a problem with the patient’s body and mind being treated separately, thereby creating problems as some patients have symptoms that come from both mind and body. This is an aspect that relates to some of the issues that have already been brought up, such as the communication with the doctors and knowledge about the disease. The nurse also mentioned that she thought the infectious disease ward was better than the last ward she worked at, as they have a counselor available, who is a person that can provide support both practically and psychologically, but she thought there still were a lot of improvements that could be made. It could be argued that only one nurse bringing this up as a problem is not enough to indicate a larger problem. However, it was also bought up in patient interviews. Patient 2 (2017) had been at another ward for treatment of psychological issues and had been moved to the infectious disease ward as she had contracted an infectious disease and this meant that the psychological problems did not get priority. This situation was already brought up when discussing the communication issues with the doctors, but it also exemplifies problems about only treating part of what made the patient sick. Another problem was brought up in the interview with Patient 5 (2017) where the patient’s friend wanted contact with a counselor. The counselor had presented herself to the patient when the friend was not there but the patient had not remembered it due to a disease affecting the mind, showing some problems with communication. The effect was that the counselor could not provide support as efficiently.

These were indications that I received during my investigation pointing towards that physical and psychological problems were not both considered enough when the patient was cared for in the infectious disease ward. This problem involves several aspects and the area could be the topic of an entire master thesis, therefore my study will only briefly go into this theme. It is also the case that I am not specialized in the medical field, therefore lacking knowledge that would be important to fully understand the issue of involving both the patients mind and body.
Even with my current knowledge it is clear that this area is something that is an important one within medicine. Lipowski (1988) argues for the importance of considering that physical symptoms of a disease can come from a psychological disease as well as a physical. He states that this means that after the physical diseases have been investigated and not found, the doctor should talk to the patient about investigating psychological issues, such as depression (ibid.). This highlights the importance of considering both the body and mind when investigating the source of symptoms, which is one part of the problem in considering both body and mind in the care of a patient. The indications of the problems detected in my study were that the patient’s psychological health was not considered enough, as Lipowski (1988) states it is important to also consider the psychological health of the patient. Research has also showed that the symptoms and progression of certain diseases are worsened by psychological stress (Cohen et al., 1999; Leserman et al., 1999), making the psychological state of the patient important to consider even for a purely physical disease.

Digitalization could help the doctors to involve both body and mind in the care of the patient, by for example letting the doctors communicate with other wards to make use of their specialty without being physically present, thereby saving time and other resources. It is also possible to have the technology indicate when problems could be due to both psychological and physical problems, making it easier for the staff to identify what the causes of the disease are. Another issue is that the doctors do not consider psychology to be a problem and are therefore not putting enough focus on it. Changing the process of how the diagnosis is done to involve psychological aspects more could be one step to solve this problem.
Chapter 5

The Prototype

There are, as discussed, several needs and areas of possible improvement at the ward. Everything cannot be solved with one solution and there are several limitations when developing something for the ward, mainly due to economical and bureaucratic reasons. For these reasons a prototype for a solution that mainly focuses on the communication and information issues was developed for this thesis. The areas that have been discussed in the previous chapters will be considered in relation to the development of the prototype.

To design the prototype I followed an iterative design process, as described in the following section, 'Designing the Prototype'. The goal was set to create an interactable prototype that showcases both needs and suggests solutions. It is not necessarily meant to be a design that is implemented but its purpose is rather to create a better understanding around the problems. The design is meant to reflect a solution that would be good to have, but might not be practical to implement at the ward, due to the many restraints.

5.1 Designing the Prototype

To create a prototype for this thesis I used an iterative design process. This means that I suggested a design and had it evaluated, then redesigning it based on the evaluation. Using an iterative approach that includes the users of the prototype helps to identify problems that is experienced when using the prototype that can be fixed in a later iteration, and evaluated further to see of the problem has been fixed (Nielsen, 1993).

I started the design process by using pen and paper for the first iterations as it is a cheap and fast way of conducting the design and leaves room for large improvements as well as new ideas (Buxton, 2010 p.138-141). In later iterations the design was done on the computer to create a better way of testing it and be more specific in how the design will look like. This process is described by Buxton, 2010 p.138 as the design funnel, meaning that the design starts out wide in the idea phase, with prototypes that are easy to change.
Then as new, higher fidelity, prototypes are produced the design becomes more and more restricted. During the different iterations I consulted several persons, a mix of people knowledgeable in different areas, as well as potential users. I started out with focusing on the usability of the prototype and then the content and what the prototype could do got more focus in the later iterations. The specifics of each iteration are described later in this chapter.

In the first iterations I consult with two students that I know since before this thesis to get feedback on how good the design is from an interaction perspective. Both of them have worked within interaction design and similar areas and one of them specializes his studies in Human Computer Interaction (HCI). The main purpose was to get feedback on the interface and how the interaction was, mainly this meant in what way the prototype was navigated and how the information was presented. Although these students are not the main target group for the design, they could represent patients that have very little previous knowledge of being in an infectious disease ward. Therefore I have chosen to take their feedback on the contents of the prototype as well. It is important to be very critical to their criticism, as they are not current users, and for that reason it was later confirmed with the actual users of the system, the patients.

The third iteration was evaluated by two patients at the ward, by printing out the design and discussing it with them in their rooms at the ward. Consulting the intended users of a prototype is a good way of improving the usability of the design and the user satisfaction (Abras et al., 2004, p.12). The patients were consulted on what they thought of the prototype and what they thought should be changed. This feedback was used for the design of the last iteration.

A lack of feedback from nurses on the prototype is a weakness in the development process. The amount of data gathered from the interviews with the nurses creates the basis for the design but it would be beneficial to receive criticism on the prototype as well. Unfortunately this was not possible due to time constraints.

5.2 First Iteration

The first iteration of the prototype focused mostly on including functionality that tackled the different problems. This iteration was done on paper, as it is an easy way getting something that can be discussed with other people. The media that was targeted for the prototype was a tablet computer, as the hardware is closed and can therefore easily be decontaminated, which is a necessity for things in the patient rooms at the infectious disease ward. As a tablet was chosen as the medium, the prototype was developed as an application.

The functionality that was developed for the application was, in no particular order:
5.2. FIRST ITERATION

- General information about the situation at the ward
- General information about the patient’s disease
- Information about the staff’s and the patient’s schedules
- Chat connecting doctor and patient
- An improved system for the patient to contact the nurses

5.2.1 General Design

To get this prototype accepted as a possible solution to the problem several other areas needed to be considered as well. One such area is that the workload of the staff is not increased as they currently have a problem with high workload, and increasing it would not be accepted by the staff. It is also important to make the prototype easy to use as the patients are often old, and sometimes not used to similar technology. The patients are also sick which makes it harder for them to perform everyday tasks at a similar level as a healthy person. These are areas that were considered for the first prototype and throughout the entire design process.

The design was made with pen and paper as it is an easy and fast way to show a concept. The focus was mainly on the different views that would be necessary to fulfill the needs specified above. The interaction aspect was also considered but not the main focus at this point. This resulted in several views that were drawn on paper to represent the different possible screens that could be viewed in the application as seen in fig. 5.1.

The following sections will describe the motivations for each view and how I thought about the design. A menu view can be reached in all other views by tapping the menu button in the top left corner, and all other views can be reached from there. The other views, that are now going to be discussed correspond, to the different needs.

5.2.2 General information about the situation at the ward

To give the patients more information about the general situation at the ward I propose a text-based view. It is already available, as seen in fig. 5.2 on the hospital’s webpage but the information is not very detailed. This can be expanded with more information and as it would be available in the application the information would be easy to access. It would also be a good idea to get information about the layout of the ward and how the staff normally behave and why. Such information could be why the nurses use rubber gloves and plastic aprons when taking tests on the patient\(^1\) which is something that non-hospital staff do not generally know the motivation for. This would make the patients more calm as they would know more about what is going on around them.

\(^1\)This is done to decrease the spread of diseases.
CHAPTER 5. THE PROTOTYPE

Figure 5.1. The design of the first iteration

Figure 5.2. The hospital’s webpage with some information about the ward (Inskrivning och Sjukvårdsvistelse 2017).
5.2. FIRST ITERATION

5.2.3 General information about the patient’s disease

Having some general information about the disease is a good way for the patient to better understand what is happening to them. This information would normally be given by the doctor and the application would not be a substitute for that but would provide a complement to how the patient receives the information. As the access to the application would be constant during the stay the patient can read up on the disease when feeling better, as well as spend more time processing the information. Nurse 6 (2017) suggested that this could be done by having access to the Swedish healthcare information system, ‘1177 Vårdguiden’. An example of how pneumonia looks in Vårdguiden’s webpage can be seen in fig. 5.3. This site is aimed to inform all Swedes about how one is affected and can judge the severity of different diseases, as a first step before contacting a doctor. As it is aimed at a broad audience with limited knowledge of medicine, this would make the websites information well adapted for the general patient at the ward. Therefore I believe that it is a good way of showing the general information about the disease. Stribling and Richardson (2016) supports the claim that patients feels more educated by receiving information about their disease from technology in the form of a computer tablet. This also supports the other themes that my prototype tries to solve when it comes to the patient receiving information from technology, both general information and information about their day.

![Figure 5.3. 1177 Vårdguiden lunginflammation (Widman, 2017).](image)

5.2.4 Information about the staff’s and the patient’s schedules

The information about the schedule of the patient is intended to be shown as a general view that fits for most of the patients. The view is intended to give a general indication of when tests are taken by the staff and when food is normally served and similar events that
play an important role in the patients’ day. This could also be complemented by having the staff’s schedule, mainly the nurses’. Having a general schedule of what happens to the patient during the day is very much connected to what the nurses are doing so the two are not that different. Having information about when the nurses have their morning meeting and are meeting the doctor and similar important tasks would be good for the patients to know so that they can adapt when they call the nurses as to not feel they are interrupting something important. This would enable the patient to take the nurses’ situation into consideration when asking for help, which was something that many patients already did by not calling unless absolutely necessary or by waiting until the nurse came to the room for some other reason to ask for help. Many patients also believed that it would be nice to be able to ask the nurses for help with minimal interference to their other tasks. But one of the most important benefits would be that the patient would feel more in control of their day, which was something that very few patient felt during the interviews.

5.2.5 Chat connecting doctor and patient

In the interview with Patient 5 (2017) the patients friend, that was present during the interview, said that it was complicated to ask questions to the doctors and that planning meetings only could be done through phone calls, which were time consuming. There was also a problem in remembering the questions that they thought of during the day when the doctor finally came. The friend suggested that there should be a paper in the patient’s room so that the patient and her could write down the questions they had to the doctors and what times she would be there so that the doctors could meet the patient at those times to include her in the care. As I have chosen to take a more technical approach, by developing an application, I have chosen to implement the functionality with a chat rather than a paper. The functionality of the chat would not necessarily be meant for real time communications between the patient and doctor, but rather for the patient to ask the doctor questions during the day. The doctor could either answer the questions in real time or wait until the daily meeting with the patient. Considering that chatting in private daily interactions has become more and more common with the rise of the smartphone and applications that make chatting more convenient there should be small barriers to implement a similar system in the ward. This would make the time that the doctor spends with the patient more valuable as they can prepare answers and do not have to think of them on the spot. It would also increase the relevant questions asked by the patients as they would not have to remember them when the doctor arrives.

5.2.6 An improved system for the patient to contact the nurses

Currently the only way for the patients to contact the nurses is through a red button in the room, that is used for anything that the patient needs from the nurses. This button is also considered to not be an emergency alarm, making it complicated for the patients to
5.2. FIRST ITERATION

relay an emergency to the staff. There are several ways of improving this system, such as having several buttons for different degrees of need or as Nurse 2 (2017) said, to change the color to something else than red as she believed old people were more inclined to press a button that is red. In this iteration I chose to create icons that represent different needs that the patients have, such as food, ‘fika’ or help with going to the bathroom. Having different buttons for different reasons for the call was inspired partially by Galinato et al. (2015). They used a similar system where the patient could call the nurses by pressing different buttons and thereby notifying the nurses what the patient wanted. The study showed a good response when the system was evaluated and I believe that a similar system would have a similarly positive response. Having a solution that differentiates calls from the patient would make it easier for the nurses to prioritize the alarms as they would know what the patients want. This would also relieve some of the stress the patients feel in having the same alarm for emergencies and non emergency. Letting the patient know that the staff understands the reason for the call would probably make the patient more comfortable in calling the staff when appropriate as they would know that the call is correctly prioritized.

5.2.7 Evaluation

After the design was completed I consulted with two students to get feedback on the first version of the application. Having students do the evaluation could be argued being less ideal than having users evaluate the design. Why I have chosen students that have knowledge on HCI is that it will provide good feedback on the general design of the application. They also represent users of the application that knows very little of the infectious disease ward. In later iterations people that are more probable users were included in the evaluation.

The first consulted person was Student 1 (2017), with professional experience in designing and developing used interfaces. He agreed that the needs were well covered but would like to see some form of entertainment as a further need after hearing that the patients only had access to a TV. He also had some critique on the design and argued for it to be more simple and explain more in text, specifically the icons to call the nurses. One other need that he saw relating to the disease of the patient was that the application should give access to the patient’s medical records to increase the trust in the medical staff. The prototype was also evaluated by another student, Student 2 (2017), that specializes and works with HCI. He argued for merging views and functions so that less clicks are required to access all functionality. Another improvement would be to always show the menu and changing the start page. According to him, having access to the journal in some way within the application would also be an improvement. He thought that the confidentiality issues that
arise from access to patient data could be solved by using the Swedish solution BankID. What differed from the other student’s opinions was that he thought that icons were more clear than text, with a combination of the two being optimal.

5.3 Second Iteration

The second iteration incorporated the feedback on the first iteration by merging functionality and adding a menu that was constantly visible, with both text and icons where applicable. Access to journals was also added as both students requested it and it was seen as a good way to build trust, as the patient can see what is done and more specific questions can be asked to the doctor. The menu was also changed to be shown at all times at the bottom in all the views. I chose to not include entertainment as there are separate applications fulfilling that need, such as ‘Netflix’ or ‘HBO Nordic’, that could be installed on the tablet. The other functionality was kept as it received positive feedback from both students.

Fig. 5.4 illustrates how the design of the second iteration ended up. This iteration was also done on paper as it is fast and sufficient to get further feedback. I spent more time on the drawing and each view was made bigger to make the functionality clearer for the next round of evaluation.

The same two students were consulted and the new design to give feedback and to see that I understood the feedback on the first iteration correctly. Student 1 (2017) liked the general design of the new prototype and we discussed whether the menu should be on top or bottom. We also discussed the inclusion of a chat with the nurses, which he saw as a good thing but he still wanted the icons as a simpler and quicker way of contacting the nurses. Student 2 (2017) believed that the new iteration reflected his feedback in a good way, with a constant visible menu and clear icons with text. He also believed that the usability had been improved, but we also discussed if the menu should be at the top or bottom of the application.

5.4 Third Iteration

The third iteration was done in myBalsamiq, which is a web-based interaction design tool for computer programs. This was done to get an interactive prototype that reflected a real application in a better way than paper. At this point the design was good enough to get a good picture of the functionality without previous knowledge on the subject of interaction design and the patients’ needs. The changes from the previous iteration were minimal. I decided to have the menu at the bottom as this would make it easier to reach on

\(^2\)BankID is an application used for identification over the Internet.
5.4. THIRD ITERATION

![Diagram of the design of the second iteration](image)

**Figure 5.4.** the design of the second iteration.
CHAPTER 5. THE PROTOTYPE

a mobile phone if this application would ever be used on one. I also chose to remove the icons to contact the nurses and only include a chat to keep redundancy to a minimum and having a chat enables more complicated communication than icons. The example used for the chat with the nurse was the patient asking the nurse for a cookie, as this represents a situation that few patients would be comfortable to press the red button for and the chat would hopefully make them more inclined to make such requests. Fig. 5.5 shows how the design turned out.

This iteration was presented to 2 patients at the ward as they are the ones that would be the users if the prototype is developed into a product. The discussion was unfortunately not done on the computer with an interactive prototype due to the contagion risk of bringing in electronics into the patient rooms. Instead it was done by printing the different views of the prototype developed in myBalsamiq on paper that was showed to the patients. This does not give the user the same understanding as having an interactive prototype as it lacks the interactive part, but given the circumstances it was the best I could think of.

Patient 6 (2017), the first patient that gave feedback on the prototype, was very positive to the idea and thought that the information that was supposed to be included was something that she would like to know more about. She also thought that it would be especially nice to have access to her medical journal and some general information about her disease, either through something like Sjukvårdsuplysningen or that the doctor wrote a short text about it. Although most of the comments were positive, she commented that there might be problems with the secrecy regarding the data, due to the laws and regulations concerning healthcare data in Sweden. On a more positive note, she thought the journal access and general information about the disease would help her get more informed about her condition and that she could remember the information given to her better, as it was written down and could be repeated. She said that

“The more you know, the better you feel”

Patient 6 (2017)

was how she viewed her stay at the hospital. The prototype could also help her relay the information to her relatives that were worried about her situation, as currently she had problems remembering the information that the doctor gave her. She suggested that it would be positive if the application could also be accessed by relatives that had an interest in the patient’s care so that they also could be more informed about the patient’s condition. One concern that was voiced during the discussion was that she did not like when people googled the problems that they had, as this information would be hard to interpret without the proper education. Therefore she thought it was nice that the prototype gave information that had been checked by the staff. The ward’s food menu was
5.4. THIRD ITERATION

Figure 5.5. The design of the third iteration.
also a thing that she thought should be included as the menu was the same for every day and she thought it was unnecessary for the nurses to run in and out of the rooms with it every day. In general she was positive and said that she would like to see the prototype implemented as it would give the patient more power and involvement in their own care.

Patient 7 (2017) thought that the idea of having an application was not very interesting, as she thought she was too old to use one. As many of the patients at the ward are very old it is important to keep this in consideration when developing any kind of prototype that is aimed at the patients. After further discussion it was clear that she was interested in having the information that the prototype would provide, but she would rather have it in paper format. Two of her relatives was there and they were also somewhat negative to using new technology such as an application, but would like more information about the status of the patient. One of them said that in other wards the patient was offered a binder with information about the general information about the ward, such as visiting times and how the ward worked. This was something they missed in the infectious disease ward. They also thought it would be good to know who the nurses with the current responsibility of the patient were, and having a schedule on the wall would be a positive thing. Overall all of them wanted the information that the prototype would provide but they did not like the technological format that it was developed for. Much of the information that the prototype could provide could also be given in another format, such as paper, if the patient would want that, which is something to consider due to the special situation of the ward with many old and sick patients.

5.4.1 Discussion on the Prototype

The prototype had an overall good reception from the people that evaluated it and it seems like a finished product of the prototype would be able to meet the needs that it was meant to handle. Overall the prototype seems to be a good initial step in developing a product that could help with some everyday problems experienced by nurses and patients. But it is also important to remember that I did not examine how one could implement the prototype as a finished product and that is an area that needs more investigation. Another important thing are the circumstances of the ward, with mostly old and very sick patients, creating some drawbacks with using an mobile application as a mean of informing and communicating for the patients. This could be solved by having other, alternative, means of giving the patient the information, which as previously mentioned could be done by paper. As even the older generations are becoming increasingly more used to technology the amount of people that could use this prototype is increasing.

Privacy is an issue that is brought up in both Carman and Britten (1995) and Caine and Hanania (2013) that both argue that patients are concerned with who have access to their data. This has been considered with the prototype not containing any information that
5.4. THIRD ITERATION

the staff do not already have access to. Considering that the information is in the hands of
the patient they have the power to share it with the people they want to share it with. The
staff should not be able to give access to the information in the application without the
expressed consent of the patient. The issue of data security has not been considered when
developing the prototype and should be further investigated if the development process
is continued.

The evaluation could be improved by involving more patients, but as the prototype was
based on the needs that were uncovered during this study, the design was developed from
a good base of information. Even though this is the case and strong support can be found
for the features of the prototype, both in the literature and in this study, it is advisable
to do more user testing before moving forward with developing a product based on the
prototype.
Chapter 6

Discussion

In this chapter of the thesis the validity, reliability and generalizability of the results of this study will be discussed.

6.1 Validity

The validity of a study refers to how well the study describes the phenomenon under investigation and in general a interpretivistic study has rather high validity (Collis and Hussey, 2009, p.64-65). In total, 12 interviews were conducted. The selection of interviewees was rather random, which also increases the validity of the study as it eliminated some biases. During the later interviews, information was being repeated, which increases the validity as a random selection with people that gives the same information shows that the information is relevant for the question that is under investigation. However, it is important to remember that the questions asked during the interviews play a large role in deciding what information is gathered, asking the wrong questions could result in gathering irrelevant information. As the literature agreed on most points that were discovered in this report the questions can be assumed to be valid.

In this study I developed a prototype that was tested on the patients, which increases the validity of both the needs that were discovered as well as the validity of the developed prototype. The feedback received directly evaluated the validity of the prototype as it was discussed how well it would function for the patients. As the content of the prototype is based on the needs, it indirectly evaluates the validity of the needs as well. I could have conducted more feedback sessions with patients to increase the validity and as I had no feedback from nurses the validity is decreased.
6.2 Reliability

The reliability refers to how precise the results are and if they can be repeated by another study. Interpretivist studies generally have very low reliability as the research is subjective, making the results hard to duplicate (Collis and Hussey, 2009, p.64). This study is no exception to the norm and the results are interpreted in a subjective way. As the results of my study is similar to other studies on the same subject the reliability of my results on RQ1 is increased. But when it comes to the development of the prototype, there is little reliability as design is very subjective and another person designing a solution might choose to go in a completely different direction. One could argue that the reliability is increased due to the prototype building on the answers from RQ1, but it is still low.

6.3 Generalizability

Generalizability can be describes as to what extent the results of the study can be applied to another setting. In interpretivism this generally means that the results of a few or even one study can be applied to another setting if the results have ‘captured the interactions and characteristics of the phenomena you are studying’. Doing so requires that the researcher have a deep understanding of the activities and behaviors that have been studied (Collis and Hussey, 2009, p.65-66).

As the results of what the needs of the patients are is backed by several studies, some quantitative, in other nations and other areas of healthcare, that raises the generalizability of those results and shows that this study can be generalized to other hospital settings. It seems to be a concurrent theme in most healthcare and as many studies show similar results, these results seem to be applicable to other wards in other hospitals as well. Although it is important to remember that some needs found in the literature does not exist at the infectious disease ward and therefore the generalizability is lowered.

Even if the prototype is developed specifically for the ward investigated in this study, it should function in other wards as well due to the needs it is based on also existing in other parts of healthcare. As the ward has isolated rooms it is possible that the prototype might only be used in other ward also featuring isolated rooms. Even if the ward has isolated rooms the other features are very similar to other wards and therefore I would argue that it should be generalizable to other wards, independent of them being isolated or not.
Chapter 7

Conclusion

As the nature of the two research questions is rather different I have chosen to split the conclusions of this report into two parts, one for RQ1 and one for RQ2. The conclusions will relate to what the results of this study are and a discussion on these.

7.1 RQ1: What are the current needs of the nurses and patients that can be met by digitalization?

This study showed that the needs of the patients at an infectious disease ward are very similar to the needs of patients found in the literature. Most needs stemmed from lack of information and communication, and the needs of the nurses were closely connected to the patients’ needs, as having calm and content patients made the job of the nurses easier. This coexistence was apparent in both the patient and nurse interviews where the nurses liked their job more when the patients were calm and content and the patients became more content when the nurses liked their job.

When I conducted the thematization of the interviews the themes under information and communication that were discovered were ‘patients lacking general information about the ward’, ‘patients lacking knowledge about what would happen to them during the day’, ‘patients lacking information about their disease’, ‘lacking communication with the doctor’, ‘lacking communication with the nurses’ and ‘care involving both body and mind’. These were all needs that primarily affected the patient but directly or indirectly affected the nursing staff as well. Looking back at the literature study one can see that several of these needs have been discovered in previous research (Tamburini et al., 2000), but have yet to be resolved. One example of an unresolved need is the involvement of the patient in their own care that is brought up frequently (Reed and Stanley, 2003; Hibbard and Peters, 2003) but very little practical change has been done to facilitate this need. Looking at the digitalization of healthcare the focus has previously been on increasing efficiency,
reducing cost as well as making the care safer (Ball et al., 2003, Noffsinger and Chin, 2000). These are the motivations of the majority of the current HIT that exist at the ward in this study. More recent studies have been focusing on increasing the patients’ involvement and general satisfaction in the care (Stribling and Richardson, 2016, Bernhard et al., 2016), but the knowledge of these problems has, as mentioned, existed in healthcare for a long time. The results of my study mostly confirm the previous knowledge on the area of the needs that the patients and nurses have but bring some new light into how these needs are connected with each other. My study also highlights that these problems still are present in today’s care, even at what by both nurses and patients is considered to be a relatively good ward. My study also discusses these issues in a more in depth way and through that it becomes apparent that many of the problems stem from the staff, mainly the doctors, having different views on how healthcare should be conducted than the patients. There is also a lack of resources that makes the staff having to prioritize their work which leads to the problems that I bring up sometimes not being considered as more pressing issues exists, such as the basic care of the patient.

I also believe that it is important to further discuss that both staff and patients considered the ward to be, relative to other wards, good. This could indicate that nurses and patients at other wards have the same needs that are found in this study. Therefore I believe it is important to conduct more research into what the needs are in other wards. The infectious disease ward mostly consists of isolated rooms for the patients and this might lead to certain problems not being applicable to other wards where this is not the case.

To finish my thoughts on RQ1 I would say that there are problems that exist and are known but not considered. Digitalization could play an important role in meeting some of the needs found in this study, if new HIT consider these needs. The research on needs of patients and nurses seems to already be known but not always prioritized in healthcare. My study gives some more insights in what these needs are and why they exists but more research is needed on the organizational issues that lead to the discovered needs being known but not solved.

### 7.2 RQ2: How could a prototype that meets some of these needs look like?

A prototype was developed and evaluated in this study. It was aimed at a general patient at an infectious disease ward that has some knowledge of technology. The prototype was adapted to be as easy to use as possible to include as many patients as possible. The user evaluation indicated problems with having older people use the prototype as they are not used to current technology. This is a problem as many of the patients at the ward are old and therefore are not capable or willing to use a new technology. But there
exists younger patients, which in this case could be considered to be below 70, that are very accepting to having another tool in their daily life at the hospital. Even for the older patient the needs met by the prototype was present and in those cases the same functionality might be delivered with another technology, such as paper for information. The workforce sustainability was also considered during the development of the prototype as this is important both to make the situation for the nurses better but also to have them accept a new HIT solution.

Research have been done to evaluate similar prototypes to the one developed in this study. As there seems to be a lack of solutions to the needs found in this study it is still valuable to investigate more solutions. My aim was to make a prototype that would solve several of the problems that was brought up in this study and therefore I took a wider approach to what was needed, compared to previous research that mainly focuses on one need. The presented solution is made to fit an infectious disease ward but could in all likelihood be used in other wards in different hospitals as well since the needs it was based on have been found in a wide variety of settings.

Finally it is important to consider that even if solutions have been developed and the knowledge of what is needed exists in literature, very few implementation have been done. To get more widespread implementation on solutions that solve some of the needs of the nurses and patients more research is required into what is needed to make the implementation happen.
Bibliography

Buxton, Bill (2010). Sketching user experiences: getting the design right and the right design. Morgan Kaufmann.

Definition of digitize in English (2017). [visited on 05/03/2017].
Faden, Ruth R, Catherine Becker, Carol Lewis, John Freeman, and Alan I Faden (1981). “Disclosure of information to patients in medical care”. In: Medical Care, pp. 718–733.
Inskrivning och Sjukvårdsvistelse (2017). [visited on 05/21/2017].
Jenkins, Valerie, Lesley Fallowfield, and Jacky Saul (2001). “Information needs of patients with cancer: results from a large study in UK cancer centres”. In: British journal of cancer 84.1, p. 48.
Kleven, Nils Fredrik (2014). “Virtual University hospital as an arena for medical training and health education”. In:
BIBLIOGRAPHY


**Interviews**

* Nurse 1, assistant, Semistructured interview (24 February 2017).
* Nurse 2, assistant, Semistructured interview (27 February 2017).
* Nurse 3, registered, Semistructured interview (28 February 2017).
* Nurse 4, assistant, Semistructured interview (1 Mars 2017).
* Nurse 5, registered, Semistructured interview (1 Mars 2017).
* Nurse 6, registered, Semistructured interview (8 Mars 2017).
INTERVIEWS

Nurse 7, registered, Semistructured interview (8 Mars 2017).
Patient 1, Open interview (2017).
Patient 2, Semistructured interview (2017).
Patient 6, Feedback session (2017).
Student 1A, Feedback session (2017 Mars 23).
Student 1B, Feedback session (2017 Mars 28).
Student 2A, Feedback session (2017 Mars 24).
Appendix A

Original quotes

As the quotes in the report are translated to English and modified so that the reader can understand what is said, this section will give the original quotes unaltered and in the original language spoken during the interview.

“Men framförallt, många säger att det är ett fängelse.”

_Nurse 5 (2017)_

“Jag får inte gå ut därute?”

_Patient 3 (2017)_

“För det tog nog något dygn innan jag fick reda på att jag låg på en infektionsavdelning, jag trodde att jag låg på en medicinavdelning.”

_Patient 2 (2017)_

“Kommer dom ut i korridoren så blir dom ju nästan utsällda liksom.”

_Nurse 6 (2017)_

“När en patient kommer hit så ska ju den informationen ske och har patienten legat ett par dagar så utgår man ju ifrån att den informationen har givits, men så behöver inte vara fallet.”

_Nurse 6 (2017)_

“Man får frukost på morgonen och lunch och middag, sen ska man sova.”

_Patient 4 (2017)_
“Det är en grej som vi har lärt oss, att man måste fråga och då får man svar men frågar man inte då får man inte svaret heller.”

Patient 5 (2017)

“Jo det är en grej, om man verkligen behöver hjälp eller en kopp te det är samma knapp där.”

Patient 5 (2017)

“Det är väldigt uppdelat och de borde ha en helhet, en enhet, att man borde behandla hela människan.”

Nurse 4 (2017)

“Och den tiden som dom träffar patienten är lite som en dålig farsa som spenderar kvalitetstid med son och vill göra så mycket som möjligt på den tiden.”

Nurse 6 (2017)

“Jag vet många patienter som glömmer att säga saker till läkaren.”

Nurse 6 (2017)

“Ju mer du vet, desto bättre mår du”

Patient 6 (2017)