



Leiden University

ICT in Business

ICT enabled communication for patients with final
stage neurodegenerative Parkinson's disease:
Development of a communication board prototype

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Date: 21/06/2015

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Acknowledgements

This thesis has been long in the making (almost a decade). Its progress has been slightly delayed by a couple of factors. The most important advice I could give to other students is to not ever buy a bar before you finish your studies. Finishing this thesis is an achievement that I initially did not expect to accomplish. Therefore, I am extremely grateful to Dr. Hans LeFever who took time out of his busy schedule to supervise the completion of my thesis and to provide me with guidance along the way. A word of thanks also goes out to Dr. Ir. Fons Verbeek who was willing to become my second supervisor without ever having met me. I would like to thank Prof. Dr. Hans Borgman and Daniel Erasmus for always believing in me. Last, but not least, I would like to thank Judith Havelaar and the exam committee, who helped me navigate the procedural requirements. Without these people, I would never been able to graduate as the last of the class of 05/07.

A lot of people took the time to meet with me to and to provide me with insights for this study. Therefore, I would like to thank Kees Kamphuis, Thea de Haan, Maarten Westmaas and Gerjanne Eppink of the specialised Parkinson center St. Maartenshof in Groningen, Els Komdeur and Christine Quak of the medical treatment center in Naaldwijk, Paula Ossenbrug of Palia homecare and Maria and Henk Kamerman. All of these people were willing to give me valuable information on the toll that Parkinson's disease and lack of communication with patients puts on everyday life. The development of the prototype would not have been possible but for several people. I would like to thank Jan Kikstra for welding such a solid stand and Trudi Kikstra for painting it (and lending out her husband to me). Jan and Trudi are always there to support me and help me whenever they can. Jasper Neuteboom also deserves mention for helping me build the communication board computer and for his valuable advice.

Finally, there are a lot of important people in my life that supported me along the way. If it wasn't for Job de Reus motivating me with the promise of three crates of beer, I might never have gotten started again. Big thanks to Pieter Bregman who has been a dear friend for many years, always providing me with constructive feedback and for being there to help out. Paul Ruczynski for always lending a hand, Koos van Marle for providing me with feedback and Thomas van Goolen for being a good friend who always motivates me. My uncle Jan Barendse, who came to my aid in time of need. And last but

not least, Fransje. My thesis is not the only thing that took a decade to complete, and I am happy that after knowing each other for 10 years, we finally found each other. I am very grateful for her, her support, and her help along the way. Many hours have gone into supporting me during my thesis and providing me with the necessary feedback. She has been an enormous help, not only with my thesis, but also in bringing structure to my life while allowing me to be myself and to be there for my parents.

I would like to dedicate this thesis to my parents: my father Ben Barendse who is the best father someone could wish for and who has been struggling with Parkinson's disease for many years now. Even though times are difficult, I am glad he is still around to make me laugh and I hope to have him stick with us for as long as possible. And my mother Riekke Barendse, who is the sweetest woman in the world and who, even though times are often very difficult for her, is always there for my father and me. She is so much stronger than she thinks and every day she lives up to her vows to be with my father, for better or for worse, by taking loving care of him.

Abstract

This study departed from the human computer interaction perspective to identify communication needs and the cognitive, perceptual and motor limitations of final stage Parkinson's disease patients as a first step towards developing a communication board that specifically targets this group of patients and thereby contributes to their quality of life. Towards this end, this study integrated the literature on human computer technology with the more applied literature on Parkinson's disease, as well as interviews with patients, their caretakers and healthcare professionals, as a means to evaluate existing communicate devices. Given that no appropriate communication tools exist to support patients during the last stage of their lives, this study developed a prototype to address these patients' communicative needs. Despite attempts to create an intuitive and simple communication board, the development process was hampered by Parkinson's disease's effect on patients' ability to process information and to operate devices. As a consequence, this first prototype cannot be called an outright success in terms of improving basic communication – especially on the part of the patient. Nevertheless, the validation tests showed that the prototype did contribute to communication between patient and caretakers as long as the caretaker used the device to initiate conversations and to entertain the patient. As such, this research has set a small step in the direction of improving final stage Parkinson's disease's patients' lives through the development of a communication board.

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Chapter 1: Introduction

Today's organizations depend on all kinds of different IT systems to ensure their daily operations [1]. The healthcare system is no exception. Hospitals and nursing homes use ICT in an increasing manner to ensure the patients' safety and to work efficiently [2]. On a smaller scale, a wide range of ICT devices are available to help patients with daily tasks [3]; from simple hearing aids to more complex personal computers. Neurodegenerative diseases, such as Parkinson's Disease (PD), Amyotrophic Lateral Sclerosis (A.L.S.), and Huntington's disease, are one area where ICT devices could improve patients' daily quality of life. These diseases work progressively and their symptoms are idiosyncratic, meaning that they differ for each patient. While one patient can function and communicate perfectly for many years, others may experience communication problems within months [4]. What all patients have in common is that at a certain point it becomes almost impossible for them to communicate with the people around them.

In this final stage of the disease, patients often have to rely on body and face language. Speech turns to mumbling and patients' thoughts are often unorganized [5], [6]. PD affects all of a patient's body parts and with time the patient's ability to register the information from his or her surroundings becomes increasingly difficult. Questions and assignments need to be repeated before the patients can act on them [7]. That this may interfere with the daily care of patients is obvious, as the patients' inability to respond directly to simple questions and commands makes feeding, bathing, clothing, and talking to them exceedingly difficult. As an indirect effect, patients' communicative limitations may also cause frustration in patients and caretakers alike. For patients, this is the case because caretakers may demand a too high attention span from them or do not provide the patient with sufficient time to process the information. For caretakers, frustration may arise when patients are unresponsive to simple requests, such as for them to open their mouths when being fed. This is particularly the case when caretakers incorrectly interpret patients' inability to pay attention as disinterest or as plain unwillingness to cooperate.

Next to the obstacles communication problems pose for daily care, this process is very frustrating for patients' daily (family) life more generally. The lack of communication affects family life for the duration of the disease. A patient may get frustrated, for

example, when he or she wants to comment on something as simple as gossip or a news item on the television but is unable to find the right (key) words. Since PD is an untreatable and progressive disease, the frustration for the patient itself of losing ways of communication also contributes to the onset of depression [4]. Patients are aware that the situation will never change for the better and that they are increasingly locked within their bodies – cut off from functional and meaningful communication with those around them. As a consequence, communication problems may also reinforce the patient's role as a patient because they stand in the way of communicative exchanges between partners, friends, and/or relatives. As such, efforts to communicate with the patient may become limited to those needed to provide daily care. Given that PD is not a terminal illness, and that patients may progressively worsen over the course of many years – if not decades – this poses a heavy toll on those close to and caring for the patients[7].

This research focuses on how technology could aid patients that suffer from final stage PD and on how technology could support communication with these patients for as long as possible. This communication, as all communication, is a two-way street; patients wish to communicate with the people around them and family members or caretakers wish to communicate with the patient. The goal of this research is to develop a communication device that could improve these bi-directional communication streams and to thereby improve the quality of life of both patients and caretakers.

Problem statement

One of the problems that arises generally when developing ICT systems for daily operations is that a mismatch may occur between the ICT developer's take on functionality and the needs of the end-user [8], [9]. As this problem crops up in all fields of ICT development, the development of assistive product devices for elderly or handicapped people is no exception [10]. When designers are not sufficiently aware of the needs and skills of such lesser abled users, they may end up designing a product of limited use to its target audience. For developers that design ICT applications for patients that suffer from a neurodegenerative disease, this means in particular that they need to take into account the very specific limitations of these end-users in terms of their constrained cognitive and motor skills. Most patients with a final stage neurodegenerative disease have insufficient motor skills and clear sightedness to operate computer devices [11].

Given perhaps the difficulties involved in designing an ICT application for this target audience, a communication board designed specifically to support advanced PD patients and their caretakers is not available yet. Even though different methods and supporting devices exist that target communication problems, these are often developed for general purposes and not specifically for neurodegenerative diseases. Most of these digital communication boards rely on the use of physical buttons or the use of sensitive touchscreens to let the patient communicate with their surroundings. These communication devices work good for patients that are temporarily or permanently unable to speak, such as patients on mechanical ventilation [12]. The general method behind these devices is that the patient presses a button and the device speaks out what the patient wishes to communicate. These communication boards are, however, not adjusted to a specific disease. As a consequence, they do not address the specific requirements and limitations of advanced PD patients – in this case their lack of sufficient motor skills to operate small buttons or sensitive touchscreens.

Next to the few communication devices that are designed for handicapped people in general, others exist that target children through simple communicative formats. These do not contain sufficient communication possibilities that would enable effective communication with caretakers or a simulation of everyday communication with relatives and loved ones. Lastly, those assistive devices that have been developed and

tested with PD patients in mind are not suitable for final stage PD patients, because these devices focus on improving existing communication like speech or movement. To use these devices you must be at least able to speak a little bit [13]. As such, developing a communication board for PD patients fills a gap in the existing offer of communication devices.

Since the progress of each patient suffering from advanced PD experiences his or her own unique trajectory in the disease, and since symptoms are not the same for every patient, developing an assistive device that addresses the needs of all final stage PD patients could be difficult. In order to remedy this problem, this study will apply Human-Computer Interaction theory to systematically inventory the communication needs from patients suffering from a advanced PD, and those of their caretakers and relatives, to ensure improvement in communication. Only through a thorough appraisal of the daily communication needs and limitations of these patients can ICT improve their quality of life.

Research objective

This research will be a preliminary study that investigates different ways of communicating with advanced PD patients through use of a communication board. The objective of the study is to determine what requirements an optimal communication board requires and whether a communication board allows for an improvement of patient / caretaker interaction. To answer these questions, this study will apply a Human-Computer Interaction approach. Such an approach departs from the interaction between users and computers to ensure that ICT devices function as intuitively and efficiently as possible [14], [15]. This approach identifies the functions and requirements that need to be taken into account during the design process of the communication board.

Cataloguing the communication needs of advanced PD patients allows for the identification of necessary functions for the communication board. . This study's main goal is to specify these functions, limitations, and of a user interface for the communication board in such a manner as to work optimally for patients suffering from advanced PD. Towards this end, it is necessary to look at the physical and mental capacities of advanced PD patients, as well as their limitations. Using the limitations of advanced PD patients, a communication board can be developed to improve communication for these patients and to address their daily needs.

The empirical part of this research is two-fold; firstly, the study will look at the different techniques and devices that are currently available- with a focus on communication boards - and the advantages and bottlenecks of these supporting devices. Secondly, the study identifies the best method to allow communication in the final stage of PD.

Research question

This research will address the different possibilities of communicating with advanced PD patients.

The main research question is:

"What is the best way to communicate with advanced Parkinson's Disease patients through the use of a digital communication board?"

During the research the following sub questions will be addressed:

Sub-question 1

"How can a Human-Computer Interaction approach be used to categorize user needs and limitations?"

The purpose of this sub-question is to see how the Human-Computer Interaction (HCI) literature supports the stocktaking of user needs and their expectance of an application's functionality.

Sub-question 2

"What are the communication-based limitations of advanced PD patients?"

By identifying the limitations of PD patients, the specific requirements of the communication board could be based on their motor and cognitive skills.

Sub-question 3

"Which communication needs are not addressed on a day-to-day basis due to advanced PD patients' inability to communicate effectively? "

In order to improve patients' daily quality of life, the communication board needs to support relevant communication problems between patients and their caretakers and between patients and their relatives and loved ones. Therefore it is necessary to identify the daily struggles and communication issues that arise during ordinary days in the life of an advanced PD patient.

Sub-question 4

"What are the current available types of communication devices and what are their strength and weaknesses?"

The purpose of this sub-question is to see which devices are available, how they work, what their limitations are, and to use the positive elements of each available communicative device in the proposal for a specialized communication board for PD.

Sub-question 5

"How can a communication board address advanced PD patients' communicative needs and which functions should it contain?"

This sub-question will combine the results of sub-question 3 with Human-Computer Interaction and User Interface Design to design a communication board prototype. The software running on the communication board and the methods to communicate need to be suitable for PD patients in the final stage.

Sub-question 6

"How does the prototype communication board affect advanced PD patients' everyday communicative needs?"

This sub-question seeks to validate the communication board by evaluating the extent to which the communication board did indeed improve the daily quality of advanced PD patients' lives by effectively addressing their communicative needs.

Answering these questions will help to specify the requirements and specifications of a communication board that is suitable for patients suffering from Parkinson's disease to aid in their day-to-day communication with the people around them.

Scope

Several types of neurodegenerative diseases exist. Next to Parkinson's Disease, diseases like A.L.S. and Huntington's disease come to mind. What all these diseases have in common is that they entail the progressive loss of structure and function of brain neurons. In effect, this means that the brain and muscles lose their functional capacity. Because each neurodegenerative disease is different, and therefore brings with it its own set of communicative needs and patient limitations, this research will focus on a single disease: Parkinson's Disease (PD). However, due to the similarities between the different diseases, the findings from this research may well be applicable to other neurodegenerative diseases like A.L.S. and Huntington's disease. Further research could investigate the applicability of the communication board designed in this study to these other types of neurodegenerative diseases. Its focus on the neurodegenerative disease Parkinson's hence forms this study's first predefined boundary. Throughout the research, the disease itself will be addressed in more detail to acquaint the reader with PD's symptoms and to specify the limitations of the patients.

The second predefined boundary consists of the target group within the group of PD patients. This study focuses only on patients suffering from, or close to, the final stage of the disease. The reason for this is that patients in this stage suffer the most from communication impairment. Developing a device that addresses their needs could thereby improve quality of life the most. In addition, their limitations are obviously the most severe compared to other stages. As such, patients require more and better care, which comes at a time when they are simultaneously less able to express their needs. This study's focus on the most difficult target group within the total group of PD patients complicates the research as an inventory of user needs and limitations needs to work around the existing communicative limitations. Nevertheless, if the study proves successful, the expectation follows that the communication board designed for this group of patients would also communicate needs for patients that suffer from a lesser stage of PD.

The third predefined boundary of the research is that it focuses on the needs of patients and their caretakers on a day-to-day basis. The possibilities of a digital communication board are endless and could perhaps also be used in the future to help patients in their daily tasks (like closing the curtains or dim the lights). For practical purposes, this

research will be limited everyday communication. This communication will be investigated in two directions; primary the patient who wants to communicate with their caretakers, relatives and loved ones, but also the caretaker that wishes to communicate more effectively with their patient.

This study's fourth predefined boundary is the limitation of finding a proper way to communicate with patients using a digital communication board. There are currently different other communication devices available - mostly for earlier stages of PD - like speech improvement tools, speech implants. etc. It is not this study's goal to categorize all available assistive technologies, but merely to focus on communication boards. Where needed or possible, such other types of communication devices will be addressed throughout this research for informational purposes.

Lastly, it should be noted that the primary objective of this study is to present an analysis of best practices and to identify patients' needs and limitations. Development of a communication board for a target group will occur in the form of a prototype. Given that PD symptoms manifests themselves in a rather unique combination within each specific patient, personalization of the communication board will be addressed where possible throughout this research. This can be achieved through a focus on how the software of the communication board could address the needs of specific patients and on how caretakers and patients' relatives and loved ones could tailor the communication board themselves to address their own specific patient's needs.

Contribution

In this exploratory study, the theoretical contribution is the development of a best-practice inventory of daily communication between PD patients, caretakers, and their relatives and loved ones through technology. The findings from this study will provide a basic framework for technologically based communication with advanced PD patients. In this framework, I identify the different methods of communication that technology provides and I identify the possibilities that communicative technology offers for advanced PD patients. This study's methodological contribution lies in its search to identify the needs of patients that are clearly unable to communicate.

In terms of societal relevance, this study's overall goal is to help PD patients in their day-to-day communication and to provide them with the means to live their lives with the dignity that the disease so often takes away. Hopefully, it will prevent depression and emotional problem for patients that feel empowered to let themselves, their feelings, and their thoughts be heard. Hopefully, it will improve the quality of life for both patients and their relatives and loved ones by allowing them to connect in a more meaningful manner and to thereby mend a bridge that the wild river called PD has often eroded over the years. PD patients are not just patients. They are husbands and wives, mothers and fathers, brothers and sisters, friends and neighbors. Improving final stage PD patients' ability to communicate through a technological device aims to take the focus away from patients' 'patient status' and to enable them to take small, but meaningful steps, in regaining these positions within their social networks.

Thesis structure

This thesis consists of seven main chapters. The first chapter introduces the research topic at hand. This information includes a general introduction, a problem statement, the research objective, the research question including several sub-questions, the thesis scope, and its contribution. The second chapter on research methodology addresses the methods that will be applied within this research to gather the necessary data. It discusses the use of surveys and qualitative interviews for the identification of patient needs and limitations, as well as the method of participant selection and the representativeness of this sample of the general population of advanced PD patients. In addition, this chapter focuses on the limitations of these methods and on ways in which to ensure the reliability and validity of this study's findings.

The third and fourth chapter discuss the Human-Computer Interaction approach and focuses in particular on the types of functions that developers need to take into account when designing ICT devices in general - and ICT devices for PD patients in particular. The third chapter discusses the theory behind HCI. The fourth chapter applies this theoretical framework to the scholarly literature on PD to provide an initial analysis of the needs and limitations of PD patients. As such, this chapter provides background information on PD to provide a preliminary identification of the limitation of patients and the challenges that patients and caretakers face on a daily basis. In addition, this

chapter also discusses the currently available communication devices, as well as their strengths and weaknesses from a PD patient perspective.

The findings of chapter 4 provide the basis for the empirical analysis of PD patients' needs and limitations in chapter 5. This chapter will present the data that was collected from the qualitative interviews. On the basis of these results, the chapter identifies the problems of communication between patients and caretakers on a daily bases and the best possible way of interaction in the final stage of the disease. The qualitative interviews will also contain opinions from experts in the field. The sixth chapter builds on the data from the previous chapter to discuss the development of a prototype digital communication board. This chapter describes in detail which steps are taken to ensure that the communication board's hardware and software match advanced PD patients' needs and limitations. After the development of the prototype this board has been tested with a few patients to see if communication works better, the same, or worse because of the digital communication board. The chapter also presents the results of this analysis. The final chapter discusses the research and provides recommendations for future research. This chapter also contains my conclusion about the usefulness of a digital communication boards for advanced PD patients.

Chapter 2: Research methodology

Research design

The desire to understand PD patients' communication needs and limitations – and the way in which technological devices could improve communication needs while taking into account these limitations – forms the basis for this research. Given that little is known about the feasibility of communicative devices to improve PD patients' communication needs, this study is an exploratory one. Towards this end, the study will apply the Human Computer Interaction approach (HCI) to catalogue needs and limitations on the basis of computer devices' general functions as identified in the HCI literature. This analytical framework allows for the classification of user needs and limitations.

Given the exploratory nature of this study, a qualitative approach is most appropriate to identify a best-practice method for communication with PD patients. Feelings of patients and caretakers, as well as professionals' experiences with treating PD patients are difficult to express in numbers and using a qualitative approach allows for an inductive view of the relationship between theory and research. As such, the qualitative approach takes the point of view of the target audience as its focal points and thereby allows for the taking stock of user needs and limitations [16]. Towards this end, the study will apply desk research of existing communication boards with qualitative interviews with patients, caretakers, and experts to gain more in-depth knowledge of patient limitations as they apply to the management of computer devices and their daily communication problems [17]. These data provide the information needed to develop the prototype communication board – as discussed in chapter 5. The following sections discuss each of these methods in more detail.

Desk research

To identify currently available communication devices for PD patients I conducted desk research to identify existing devices and to determine their strengths and weaknesses. This analysis departs from the functions identified in the HCI literature and applies the information about PD patients identified in chapter 4. Interviews about current innovations with professionals that work in the Parkinson field supplied additional

data. Parkinson interest group ParkinsonNet provided the names of Parkinson experts approached for this purpose.

Survey

For reasons of conciseness, it should be noted that this study's preliminary research proposal also included a quantitative component in the design. Given that several of the problems I encountered while setting up the quantitative part of the study proved formative for this study's final research design, I will discuss them here in more detail. The initial research design contained a part where I would approach advanced PD patients and their caretakers online to ask them questions regarding both patients' communication needs and limitations, as well as caretakers' communication needs. In order to identify possible survey participants, I approached the organizers of six meetings of the *Regionale Parkinson Café's* (Regional Parkinson Meetings) organized in November 2014 in the Zuid-Holland and Noord-Holland provinces. These meetings form a platform where PD patients and their caretakers meet to exchange experiences and to attend lectures that discuss various aspects of the disease. The initial plan was to visit these meetings in order to meet patients and to create a mailing list for the online survey.

This plan did not work out because of two reasons. Firstly, these regional meetings form a meeting ground where patients seek support. In several cases, the organizers proved unwilling to authorize my visit, as they thought that people might feel uncomfortable when being confronted with what the disease might have in store for them in the future. Given that these meetings are organized to create a safe environment for patients, organizers were afraid that my presence might counteract this goal. Secondly, in those instances where organizers did approve of my visit (Parkinson cafes Amsterdam and Haarlem), attendants turned out to suffer from earlier stages of the disease. Indeed, it soon became clear that advanced PD patients are physically and mentally unable to participate in these meetings. Patient A and caretaker A form the only exception to this rule. Their case will be discussed in more detail below.

In addition, I visited a specialized Parkinson hospital in Groningen and a Parkinson nursing home in 's-Gravenzande to personally conduct surveys with patients and nursing personnel. Given that final stage PD patients often end up in hospitals and

nursing homes, these are important environments within which to conduct research. Nevertheless, it soon became clear that administering a survey to advanced PD patients, who often encounter difficulties understanding their surroundings, would prove too intrusive for the patient. Ethics dictate that the patients' care, and not the researcher's needs, should hold a central position in the research design [16]. Given these developments, it seemed advisable to alter the research design and to substitute the quantitative survey with a qualitative study of patients' communicative needs and limitations among carefully selected respondents.

Qualitative Interviews

In light of the problems encountered while setting up a quantitative study, this study mainly relies on qualitative interviews with two carefully selected patients, several of their caretakers, and relevant experts. The interviews followed a semi-structured format [18] in order to leave room for the addressing of more specific needs and suggestions. The interviews started with a quick review of the background of the interviewees. Additional questions focused on their interaction with patients in daily life and their personal experiences. What were the patients still able to do? What frustrated patients and caretakers the most and how did the disease progress within different patients. By asking direct questions f.e. "Do you think the majority of the patients in the final phase of the disease could still press a button" a clear conspectus could be created of final stage PD limitations and of course the possibilities for communication through a communication board. The semi-structured format also left room for discussions about personal issues and frustrations (see appendix 2 for a general overview of the interview questions). At the end of the interview, I summarized the answers back to the respondent as my approach to the interviews was the so-called student-tutor approach in which I took on the role of a student [19].

The interview questions clearly differed somewhat according to the type of respondent at hand. Interviews with PD patients and their caretakers focused on day-to-day communication problems: which communication issues did the PD patient, their caretaker and family and friends face and what effects do these problems cause? Does the patient have trouble showing his or her emotional state, can they point out if they are in pain and how severe this pain is? The purpose of the interview with the patients was primarily to see where they miss communication the most. Next to seeking to rank-

order the needs of the patients and their caretakers, these interviews also focused on the extent to which patients could still operate hand-held computer devices. The interviews with the experts (f.e. Parkinson's doctors and nurses) focused on their experiences whilst working with different PD patients. In their professional opinion, to what extent can patients still communicate and function and what is missed mostly by the patients and by the experts themselves in their contact with the patients. More importantly, I asked these experts to give their professional opinion about how they think communicative technology could aid advanced PD patients. Table 1 provides an overview of the various respondents that participated in this study.

Tabel 1: Interviews

Name	Function: patient/caretaker/expert	Date and location interview
Kees Kamphuis	Coordinator Parkinson section	November 27, 2014 St. Maartenshof, Groningen
Thea de Haan	Parkinson Consultant / Specialist	November 27, 2014 St. Maartenshof, Groningen
Maarten Westmaas	Physiotherapist	November 27, 2014 St. Maartenshof, Groningen
Gerjanne Eppink	Spiritual Chaplain	November 27, 2104 St. Maartenshof, Groningen
Paula Ossenbrug	Nurse / Homecare	January 27, 2105 Her home, Poeldijk
Els Komdeur	Occupational therapist	December 11, 2014 Pieters Behandelcentrum, Naaldwijk

Christine Quak	Speech Therapist	January 13, 2015 Pieters Behandelcentrum, Naaldwijk
Patient A	PD patient	January 14, 2015 Their home, Haarlem
Caretaker A	Caretaker of Patient A	January 14, 2015 Their home, Haarlem
Patient B	PD patient	December / January, 2015 Their home, Naaldwijk
Caretaker B	Caretaker of Patient B	December / January, 2015 Their home, Naaldwijk

The selected respondents cover all three categories: patients, caretakers, and experts. As noted above, during the initial stages of the research it became clear that many patients might experience an interview as something intrusive and frightening. I therefore relied on convenience sampling to select two patients and their direct caretakers (family members) on the basis that they saw the opportunity to share their experiences as something positive [20], [21]. Patient A and Caretaker A agreed to an interview during a meeting at the Parkinson Café in Haarlem. They were very open about the disease and about how it affects their lives and they were more than willing to agree to an interview at their home. Patient B and Caretaker B are close relatives that naturally agreed to participate in this study. Although the selection of family members may normally be frowned upon as a bad research practice, in this instance it resulted in the selection of respondents who could be interviewed in a safe and unobtrusive manner and thereby upheld the ethical principle not to harm participants [20].

Clearly, the decision to include only a very limited number of patients in this study raises important methodological questions about the representativeness of these respondents vis-à-vis the entire population of final stage PD patients [16]. Ensuring that these respondents likely felt safe when participating in the interviews, however, likely warranted that increased levels of stress did not interfere with patients' responses to the questions. As such, the selection of only two respondents sought to increase the

internal validity of this study's findings [16]. At the same time, interviews with several experts and therapists in the study tested whether the findings from these two patients could be generalized to the entire group of final stage PD patients. The experts and therapists included in this study cover a wide range of specialisms and deal with the professional care for PD patients on a daily basis.

Prototype

The results of the desk research and the qualitative interviews allow for the identification of the most important features and the capabilities of final stage PD patients. Using proven Human-Computer Interaction concepts enables the development of a prototype. Development of the prototype focuses in particular on the hardware and software requirements of the digital communication board. Given that this is an exploratory study, rapid prototyping enabled the development of a model for a future prototype as well as a test of the findings of this study [22].

Validation

Validation entails the testing of the effects of the communication board prototype to evaluate whether it indeed increases patient's communication skills. Because the communication board comprehends multiple communication techniques – as will be discussed in more detail below – validation also enables identification of the most effective method of communication for each patient or patient type. When testing which strategy proves most effective, it is important to provide a range of responses rather than single yes/no options to assess the strength of efficacy [23].

Validating the results of the study, the requirements, and the prototype, is a proper way to find bottlenecks for further improvement. By validating the prototype with a selected group of actual end-users, it is possible to find out which problems users experience in using the device. The importance of validating the design with the users is to prevent the finished product to be a reflection of the designers instead of the actual users [24]. The validation survey consists of various parts (see appendix 3 for an overview of the questions). The survey starts with general questions that ask which communication method functions best and whether communication has improved (general functioning). In addition, it contains questions that evaluate whether the range of

communication topics is useful and exhaustive. In a more specific manner, it evaluates whether the patient's ability to communicate basic and necessary requests, and on other types of topics, has improved (needs). Lastly, it contains questions regarding the ease of use that evaluate whether patients are able to operate the device (limitation).

The questions were answered at the end of this study after creating the prototype and after having provided patients with the opportunity to use of the prototype. Due to the communicative limitations of the PD patients, the validation of the prototype by the PD patients will be undertaken in collaboration with their caretakers. Given the poor quality of life of advanced PD patients, the validation of the results needed to occur in an unobtrusive manner in order to not give the patients any additional stress. Therefore, the prototype was only tested in a convenience sample of patients that had also been selected for the interviews with the consent of the patient and the caretaker. Although this declines the validity of the findings, as it is unclear to what extent these patients are representative for PD patients more generally, this validation test does allow for the identification of some initial strengths and weaknesses of the prototype. Further research might develop a more advanced prototype and test this communication board in broader samples of patients – although the same ethical considerations would confront such a study as are at play here.

Chapter 3: Parkinson and Human Computer Interaction

Human-Computer Interaction

Human-Computer Interaction is a self-explanatory term for the interaction of humans and computers in the widest sense. HCI is fundamentally an information-processing discipline [25]. It comprises the area where psychology and the social sciences intersect with computer science and technology [26]. As such, its history goes back to the advent of the use of technology in daily operations. More than a century ago, before the introduction of computer technology, Frederick Tayler (1911) already employed such new technologies and methods to improve work practices by the use of moving pictures and statistical analysis. The two World Wars accelerated development efforts that focused on matching people to jobs, training them, and then designing equipment that could be mastered more easily. In early computing, people were employed in three roles: management, programming and operation. Managers specified the programs that needed to be written, the programmers created the program and the operators made sure the program could run. Each of these roles subsequently became a major focus of HCI research [27].

Over time a lot has changed, as computer devices switched from vacuum tubes to transistors and eventually to personal computers. Nevertheless, the general principle of HCI as the study of effective computer management, programming, and operation as it relates to human users has remained the same. HCI researchers analyze and design specific user-interface technologies to develop optimal new applications of technology. Although HCI started out on a small scale with the use of icons for visualizing data, it now comprises the study of a wide range of interactions between human and computers [28]. As such, HCI provides important insights into how computerized devices can be designed for specific populations or specific types of users.

Developing a communication device using HCI means taking the human factor into account. This is important because humans tend to act in an unexpected manner and differ from one another. It is a challenge to identify specifications that support a larger group of people. Focusing on the human factor allows for the specification of the wishes and the needs of users of the product or application. The interaction of a user with an application or device requires understanding of three components: 1) the cognitive,

perceptual and motor capabilities of the user (limitations), 2) the task to be accomplished (needs), and 3) the device used to accomplish the task (function of limitation and needs) [29]. The following sections address these three components in more detail to specify the factors that need to be taken into account when designing a prototype communication board. Subsequent sections link these factors to the limitations and needs of PD patients so that these can be taken into account in the design process.

Needs: The task to be accomplished

Researchers and designers dealing with HCI apply a range of perspectives. When studying which tasks need to be accomplished, researchers apply the tool perspective that focuses on individual use of an application. The application is seen as a toolkit that provides the user with all necessary tools to do his or her work. The tool perspective works very straightforward: the user chooses a tool, uses it and evaluates the result. The skills and qualifications of the future users are the most essential prerequisite of the design process. So-called 'requirements identification' allows for the ascertainment of the needs of these future users, or stakeholders. The definition of a stakeholder is as follows:

“A stakeholder is a person or organization who influences a system's requirements or who is impacted by that system.” [30]

Requirements determination is a critical phase in development of computer technology and has had an effect on the entire development process [31]. In general, when developers seek to gather the requirements for the development of a new application or product, they look at your target group as a whole and try to identify their wishes. In most cases, a single application or product is developed which would be suitable for most members of the target group.

What aspects need to be taken into account during requirements identification? According to Ross and Schoman [32], it is important to create a “functional specification” of the tasks the system needs to accomplish. Masciaszek adds that this process takes “the narrative customer requirements as inputs and constructs specification models as outputs. The models ... provide a formal definition for various aspects (views) of the system” [33]. In the process, the non-functional specifications –

or the limitations to cognitive, perceptual and motor capabilities that have been described above – play a constraining role in the guiding and validation of the modeling work.

Limitations: Cognitive, perceptual and motor capabilities

Whereas the tool perspective focuses on the content of the interaction between humans and computers, the dialogue perspective focuses on the way in which the user operates the application [34]. When studying the effect that cognitive, perceptual and motor capabilities have on the user's ability to operate a computer, developers apply the dialogue perspective. This means that humans and computers are considered partners in a dialogue. The researcher focuses on the individual context of the user to identify what the user sees while communicating with a computer. This perspective is particularly useful in designing the user-interface of an application as it addresses the way a user interacts with a computer. The ideal way of communication is a command language that matches to the human language as close as possible [35]. Both spoken and written communication must be possible [34]. In the process of designing a global user-interface (GUI), however, the cognitive, perceptual, and motor capabilities of the user need to be taken into account.

Cognition in HCI refers to the process by which users become acquainted with things or with the way in which people gain knowledge. Human thought progresses take place in a dialectical relation to a person's pre-understanding and background. Only a small part of the pre-understanding and background of a person is relevant during an interaction process. This part is called the operative cognition (Nygaard and Sørgaard, 1985) [34]. The tasks that users complete with computers require a large amount of detailed cognitive processes and usually these processes occur simultaneously. As the designs of interactive procedures have an enormous number of details, increased complexity of the global user-interface cause problems for the user. The cognitive aspect is more relevant to the designs of computers and applications than other – traditional – machines. Over the years the function of a microwave or car has not changed much. Of course there are new techniques and functions, but the essence of the product stays the same. Human cognition in the context of computer design, on the other hand, is difficult because the tasks and problems from computers are large and complex and may quickly change [36].

In addition, each user experiences a user-interface differently. Therefore it is important to recognize user *perception* of interfaces and to understand the possible problems when trying to communicate on a two-dimensional screen [37]. The users are presented with information through an interface and this information needs to be as clear as possible for the user to understand. The perception of users is an active process. Human's visual system is a remarkable thing, as it allows us to see and understand objects by day, night, etc. While designing a user-interface, a designer should always keep the users in mind. This affects all parts of the design: from shapes to colors. If a designer creates an application with a pink background, yellow buttons and white text on these buttons, the application is not only unattractive, but users will have difficulty identifying the application, the buttons and what they are for. Buttons need to be large enough and positioned in a logical place, as evaluated from the user's perspective. Designers also need to address navigation throughout the application and make sure all information / tasks are located on logical places [38].

While designing an application, the designer does not only need to take the visual / logical aspect into account. The *motor skills* of the end-user are also very important. Motor skills are the essence of communication between a user and an application. A user types on the keyboard and letters appear in a field. A user moves the mouse and clicks on a different field and this field is selected. Applications nowadays combine keyboard, mouse, and sometimes even touch screen input. With regular users, this might go automatically, but when designing for handicapped, visually impaired or physically impaired people this is a very important aspect [39]. If a user has limitations and one or more of the above input methods are not manageable by them, the designer needs to take the motor skills of the end-user into account. The guiding question for developers is: "how is the user going to interact with the computer or application?"

Development for disabled and elderly people is more complicated than development for the average user because more factors need to be taken into account. Most general users have at least some computer skills, excellent motor skills, clear vision, and are able to make analytic connections in using an application or computer. Disabled and elderly people – on the other hand – may experience problems performing the most basic tasks. During the development of the prototype, the end-users should therefore be taken into consideration to a larger extent than is the case for more regular hard- and

software development in order to establish what Ross and Schoman (1977: 7) call the “design constraints.”

Validation: The device used to accomplish the task

John Kammersgaard advises to always focus on more than one perspective whilst designing or developing with HCI. It is a common mistake to focus on the main purpose of the application and to ignore other smaller aspects, such as the layout of buttons in an application that has the primary objective of analyzing data. This is a mistake because an analyst needs to be able to control the application correctly to analyze the data. Also if information is not structured properly, (human) mistakes could be made [34]. Developers tend to know what users want in general but they have a different view on the new application. They look at general functions and forget that end-users have to use the application on a daily bases. This could lead to frustration if the end-user has to take five steps to let the application do something small. Or the user could expect something to be ‘logical’ when the developer has no idea that the user expects that. The validation process, described in more detail above, allows for an evaluation of the extent to which the prototype addresses the needs of users, while taking into account their limitations.

Chapter 4: Designing communication devices for PD patients

This chapter contains two separate parts. The first part applies the HCI framework described above to the scholarly literature on PD to provide an initial analysis of the needs and limitations of PD patients. As such, this chapter provides background information on PD to provide a preliminary identification of the limitation of patients and the challenges that patients and caretakers face on a daily basis. The second part of the chapter discusses the currently available communication devices, as well as their strengths and weaknesses, in light of the limitations to the use of technology identified in the first part of the chapter. For each assistive device the strengths and weaknesses are addressed.

Part 1 – HDI and Parkinson's Disease

Needless to say, the needs and capabilities of patients suffering from PD are completely different than those of 'regular' users of applications. To determine the specifications of the communication board, the effect of PD on patients' ability to operate devices needs to be identified. Parkinson's disease is a synucleinopathic, idiopathic and progressive multisystem disorder that advances in a topographically predictable sequence. In laymen's terms, this means that it is a disease of spontaneous origins that progresses over time and that affects multiple areas of the brain and body. It advances according to generalizable patterns. As the disease progresses, it damages the nerve system, the use of body parts, and movement [40]. As a consequence, brains signals no longer reach their destination (the muscles), causing tremors or stiffness, motor failure, speech impairment, imbalance, and eventually loss of sight and loss of cognitive skills. This latter development results in Parkinson dementia and hallucinations. As the disease progresses, initiating a movement can become more difficult [4].

Needs and stakeholders

It is expected that PD patients and their caretakers can benefit profoundly from a communication board. This is the case because changes in communication are almost inevitable for patients suffering from PD [7]. *Communication problems* often start to occur in the earlier stages of the disease, as the patient's voice may change. Alterations in articulation are a problem for almost every PD patient. Speech is typified as monopitched, imprecise and dysfluent [41]. At a later stage of the disease, speech may

be impaired completely. Next to verbal communication, non-verbal communication may also be inhibited as PD patients often suffer from tremors, lack of mobility, and imbalance. Once again, these problems increase as the disease progresses [7], [42]. Nevertheless, these symptoms and accompanying communicative limitations manifest themselves differently in each patient. It is this study's expectation that the development of a communication board may improve patients' communicative abilities markedly and that it could thereby contribute to their daily care and quality of life.

Limitations

PD puts several important constraints on the design of a communication board due to its invasive symptoms. Firstly, the above-mentioned *communication problems* – which may vary between patients – imply that the board should allow for multiple communication types to allow for variance between PD patients. In addition, the board should not (necessarily) rely on spoken commands.

Secondly, PD affects the patient's *cognitive skills*. PD patients often suffer from cognitive and behavioral impairments. These may be attributed to dysfunction of multiple systems associated with the disease – such as the brain – that are not necessarily related to motor symptoms [43]. In addition, many PD patients suffer from tremors and hallucinations [44] that impede effective communication beyond the purely verbal problem. This means that the thoughts of patients may be very unorganized, as approximately one quarter of patients suffer from dementia [45]. As the disease progresses, the risk for dementia increases [6].

Developing a tool for patients in general – and in the final stage of the disease in particular – could be impeded because the speech problems and dementia complement each other. In practical terms, this means that the communication board needs unique, out-of-the box, communication methods that do not rely on spoken commands and that do not require the patient to process long sentences or large text segments, abstract concepts or complicated navigation. Instead, such communication methods need to be more basic, focused on images and association, sounds, photos and drawings.

In addition, PD patients suffer from severe *motor limitations*. The tremors that many PD patients experience severely are one particularly well-known form of motor limitations. Nevertheless, the occurrence of tremors varies dramatically between patients; some

individuals never develop tremors while others deal with them on a temporary or permanent base [41]. In addition, 40% of patients with PD suffer from tactile hallucinations which complicates communication by tactile movements [46]. Once again, this poses problems for the development of a communicative device because many patients are unable to coordinate their movements and/or handle small devices such as telephones and remote controls. As a consequence of this limitation, patients should be able to operate the communication device in a robust manner. This means that it should be designed without small buttons, without a complicated keyboard, and that it should not be designed as a hand-held device. Instead, the communication board needs to be as simple as possible and it should be designed as a very stable stand-alone device. Any input-function, such a keyboard, drawing function, or touchscreen should be large, not too sensitive, but easily manageable.

Lastly, many patients suffer from *visual impairments*, such as troubled vision, double vision, misplaced vision (seeking objects in a different location than they actually are), and the inability to distinguish contours [47]. The problems this poses for users of the communication device is that they are unable to read small letters, to operate small buttons, or to distinguish between shapes. The communication board should therefore provide a very large screen. In addition, its internal software should contain multiple options for clear colors, high contrast, and sounds that can be adjusted to the patient's capabilities by their caretaker. Table 2 provides a preliminary overview of the constraints that PD puts on the development of the communication board prototype and illustrates the way these limitations might be addressed.

Tabel 2: PD patient limitations and their consequences for GUI design

Limitation	Problem for design	Solution
Communication problems	Not every patient experiences similar communication problems; patients may be unable to speak	Implement multiple ways of communication in the GUI that do not (necessarily) rely on spoken commands
Cognitive impairments	Patients suffer from hallucinations and dementia; thoughts are	Creation of basic communication methods that focus on images and

	unorganized	association, sounds, photos and drawings, triggering recognition
Motor limitations	Patients suffer from tremors, stiffness, and/or tactile hallucinations.	Simple communication board, designed as a stand-alone device. Large, insensitive, but manageable, input functions
Visual impairments	Patients suffer from double, troubled, and/or misplaced vision, and/or are unable to distinguish contours	Large screen, GUI with clear colors, high contrast and clear sounds that can be adjusted

Part 2 - Available communication devices and assistive technology products: an evaluation

A wide range of communication tools is available on the market. Nevertheless, one limitation of these communication tools is that they tend to be designed for general purposes and not specifically for patients suffering from a neurodegenerative disease. Nevertheless, it is important to review these products before embarking on the process of building a prototype. If existing communication tools already address advanced PD patients' communicative needs relatively well, it would be hard to defend that a new prototype communication board needs to be built from scratch.

Go Talk Go Talk is a product range produced by the Attainmentcompany with a focus on children's communication. Nevertheless, many handicapped people use these communication boards as well. The different types of boards focus on 'button-to-speech' functionality which allows the handicapped to form a sentence by pressing different buttons on the communication board. Alternatively, they let the communication board 'speak out' a single activity, such as 'I would like to eat'. This communication board's major strength is that it has very clear icons, which can be understood by the majority of users. In addition, the device looks like a large calculator and it is simple to use through use of plain physical buttons. On the downside, the device and the buttons are small. This makes it impossible for final stage PD patients to

use the device. In terms of communicative features, the buttons only contain single icons. This limits the possibilities of using this device to further meaningful conversation or to address a multitude of conversational settings.

<http://www.attainmentcompany.com>

Vidatak Vidatak is a communication application for the iPad that allows patients to communicate with their caretakers through use of a set of simple categories and relatively big buttons. It also allows the patient to point out pain on a sketch of a human body and how severe this pain is. In order to operate the application, the patient selects a category, which is followed by further options, such as *I am* nauseous or *I want* water. Its extensive possibilities form the strength of the Vidatak board. By using categorized actions, its developers managed to put a lot of commands in a relatively small application. This also forms a weakness, however, as navigation could strike inexperienced users as unclear and complex. A second strength is that the icons on the touchscreen provide clear options for patients that are unable to speak. The weakness is that the patient needs to have excellent cognition and motor skills since the application runs on a very small screen.

<http://www.vidatak.com>

Minspeak Minspeak is an application that forms sentences through the use of icons. A patient can combine multiple icons to create a complete sentence. Minspeak exists of multiple images that the patient needs to put in an order followed by a category image that explains the selected image. Users should indicate if words should be used as a verb, noun or an adjective. By combining the images, the devices can speak out a full sentence. This so called 'icon sequencing' requires the patient to 'learn' a new language to communicate with. The strengths of this device are its ability to form a lot of different sentences and to use words in more than one way. The major problem with this device is, however, its complexity. The website shows a lot of examples of people happily using Minspeak, but I myself had trouble understanding and working with the way sentences are build. It is quite a challenge for patients and caretakers to understand the meaning

of icons, and the choices - is something a verb, noun or adjective – are overwhelming. As such, this application is definitely too difficult for final stage PD patients that are oftentimes unable to process information.

<http://www.minspeak.com>

SpeechEasy This device uses choral effects to help patients that speak very softly or stutter. Instead of amplifying sounds, the device alters the sound that the patient hears. This ensures that patients hear their own sound differently: both with a slight time delay and at a different pitch. This creates a natural phenomenon known as the 'choral effect', which helps patients to speak more clearly and louder. The strength of this device is that it could aid a large group of patients in the earlier phase of the disease. It stimulates the speech of the patients and helps them to communicate with their surroundings. The strength of this device is also its weakness; the patient needs to be able to speak for the device to function and be supportive. As such, the device is of little use in promoting speech and communication in final stage PD patients.

<http://www.speecheasy.com>

SpeechVive SpeechVive is a communication device similar to SpeechEasy. The major difference is that SpeechVive plays a background sound / noise when the PD patient starts to speak. This sound resembles a room full of people talking during a party. This sets off a natural cue for the patient to speak louder and clearer, based on the involuntary reflex known as the Lombard effect. SpeechVive is developed especially with patients suffering from PD in mind and it seeks to contribute to patient's ability to speak. The strengths and weaknesses of this device are similar to the SpeechEasy device. It could support a large group of patients, but these patients need to be able to speak. As such, this device is not useful for final stage PD patients.

<http://www.speechvive.com>

Tabel 3: Available communication devices overview

Device	Strength	Weaknesses
Go Talk	Pictograms (CI) Simple, just buttons (ML)	Small buttons (ML) Small device (ML / VI) Limited (CP)
Vidatak	Pictograms (CI) Extensive possibilities (CP)	Small buttons (ML) Small device (ML / VI) Complex navigation (CI) Touch sensitive (ML)
Minspeak	Lot of words possible (CP)	Small buttons / icons (ML) Too difficult for a PD patient (CI)
SpeechEasy	Early phase PD, better articulation (CP)	Improves speech, but speech is necessary (CP)
Speechvive	Early fase PD, better articulation (CP)	Improves speech, but speech is necessary (CP)

CP: Communication Problems

CI: Cognitive Impairments

ML: Motor Limitations

VI: Visual Impairments

Next to these four devices, other assistive technology products (ATPs) are available to people that suffer from a physical disability. Nevertheless, these ATPs do not provide a useful means to address communication problems in the final phase of PD. This is the case because the way in which these devices – such as Stephen Hawking’s custom-built device – require input. Such input may vary from alternative keyboards and joysticks to electronic pointing devices and sip-and-puff systems. Given that all of these options

focus on the input of information, they all expect the user to have full and good cognition. With PD patients, this is unfortunately not always the case. Also, most devices tackle a single problem (input / expressing yourself), and almost all of these products are small enough to fit in a handbag. This makes them impossible to use by advanced PD patients. A device that is able to tackle the combination of not being able to communicate, cognitive impairment, motor limitations and visual impairment is nearly impossible to find.

As already discussed in the introduction to this study, the current range of available communicative devices does not address the communicative needs of advanced PD patients in an adequate manner, nor does it take into account their mental and physical limitations. The following chapter provides a first step towards filling this gap through its in-depth analysis of user requirements on the basis of interviews with key stakeholders. This first step will allow for the creation of a prototype that matches advanced PD patients' communication needs.

Chapter 5 – Requirements analysis of PD stakeholders

This chapter builds on the theoretical framework and the analysis of HCI development for advanced PD patients presented above. Given the lack of existing communicative tools that could be used effectively by final stage PD patients, this chapter provides a first step to building such a communicative tool through an empirical analysis of interviews with PD patients, caretakers, and experts to identify their communicative needs and limitations in more detail. On the basis of these results, the chapter focuses on the communication problems that patients and caretakers deal with on a daily basis and the best possible way of interaction in the final stage of the disease. As such, the chapter identifies the way in which the different stakeholders perceive of the usefulness of the digital communication board, the requirements of these stakeholders, and how these determine the planned processes and interaction styles of the communication board prototype.

Stakeholders

As discussed above, the end-users of a product form the most important stakeholders whose requirements need to be taken into account in the development process. With the development of the communication board, the main end-user – or stakeholder – is the final stage PD patient. However, since most patients in the final phase of the disease require assistance from their caretaker, this caretaker is an important stakeholder as well. Lastly, external professionals that interact with patients on a daily or weekly basis need to be involved in the development of this system as well. These professionals operate in a more distant environment from the patient and are able to identify needs as seen from an outsider perspective. Specification of their general communications needs vis-à-vis the patient would enable them to provide care more effectively.

As such, the stakeholders can be listed in the following order of importance: 1) the final stage PD patient, 2) the immediate caretaker, either at home or at the nursing home, and 3) external specialists, such as ergo therapists, speech therapists, physiotherapists, neurologists, etc. This chapter looks at the role that the communication board could play for groups of patients and caretakers in general, but its dominant focus lies on an individualized approach. Although each target patient may be in the same phase according to the “Unified Parkinson’s disease rating scale,” the disease’s progress and

effects differ for each patient. The primary focus lies therefore on the provision of customized value to the patients as end-users, rather than designing and developing a fancy communication board loaded with nice – but useless features [48].

Stakeholder perceptions of the problem

A first finding from the interviews is that each group of stakeholders has its own view of this project. The patients' perspective is slightly different from the perspective of the professional stakeholders. The professional stakeholders focus mostly on the *best possible ways* of communicating for the general population of patients suffering from PD whilst patients and their caretakers look at communication on a daily basis with the *quality of life* of the individual patient in mind. Both perspectives will be taken into account in the development of the prototype so that it will be applicable to both individual patients and to larger groups of patients more generally and/or simultaneously.

The interviews showed that, even though individual patients have different needs, both patients encounter similar problems in communication. In addition, both patients, as well as one of their caretakers, note that communication problems result in frustration, as can be gauged from the following quotes:

*"It's unbelievable frustrating to be unable to say what you want to say. I worry a lot and nobody can take these worries away from me. This often depresses me."*¹

*"He often cries when we are in bed and I am unable to find out what is the matter"*²

*"I am fortunately still able to speak a little bit, but phone calls already frustrate both me and the other party"*³

The interviews with the experts confirm that these types of problems are common for final stage PD patients, although the severity of the problem may differ for each patient. Experts note that "the problems with communication are the patient's own speech, speaking monotone, speaking soft and variably and unintelligible"⁴ and that

¹ Patient B (Naaldwijk)

² Caretaker B – Caretaker of patient B (Naaldwijk)

³ Patient A (Haarlem)

⁴ T. De Haan – Parkinson consultant / specialist (St. Maartenshof, Groningen)

communication mainly relies on body mimic, although even this may be limited.⁵ The experts also note how all of the final stage PD patients they see would like to express themselves better and how they often feel unheard, unnoticed and have difficulties coping with the communication problems associated with the disease. In addition, experts note how communication problems interfere with their daily care for and treatment of final stage PD patients:

*“The problem is addressing their actual needs. Communication is so difficult that you need to get the information with the most basic communication methods. The lack of face mimic is also very difficult. Everything is really limited and communicating becomes more and more difficult.”*⁶

Experts also mention that knowing a PD patient helps enormously. If a caretaker sees a patient on a daily basis, he or she gets used to the way of communication and the very limited body mimic. This helps create an understanding of the feelings and wishes of the patient. Most patients that suffer from PD end up in nursing homes when they reach the final phase of the disease. The upside of this development is that nurses get to know the patient, which improves communication. On the other hand, relatives and friends may only come by once a week or month. This means that it becomes increasingly difficult for patients to maintain communication with such personal contacts that are not accustomed to the patient's personal communication style. In the end, patients may end up only being able to communicate with their daily caretakers:

*“We have also patients in our section that are completely unintelligible. If you work with patients on a day-to-day basis you get to know the patient and you will have an idea what the patient is trying to communicate. However for an outsider or a friend or relative that is visiting once every few months it is impossible to communicate with the patient.”*⁷

*“We have 24 patients in our section and I would say that about 66% is unable to speak to someone that doesn't know them on a day-to-day basis”*⁸

⁵ T. De Haan – Parkinson consultant / specialist (St. Maartenshof, Groningen)

⁶ C. Quak – Speech therapist (Pieter van Foreest behandelcentrum, Westland)

⁷ K. Kamphuis – Coordinator Parkinson section (St. Maartenshof, Groningen)

⁸ M. Westmaas – Physiotherapist / Scientific research coördinator (St. Maartenshof, Groningen)

Requirements

The requirements for the communication board are gathered from the interviews with patients, caretakers, experts, and from personal experience. After gathering the results from the interviews, respondents turned out to agree about a lot of the basic requirements. These requirements are discussed below as hardware requirements, general software requirements, and communication requirements. During the interview process, it became clear that respondents also regarded communication as something larger than the basic forms of communication needed to complete daily tasks like eating, drinking and grooming. Instead, if the communication board is to truly provide the patient with a higher quality of life, the general consensus was that the communication board should allow for the expression of feelings, memories, and stories. These wishes are collected in the last part of this section: other communication requirements.

- **Hardware requirements**

What should the communication board's hardware look like?

- **General Software requirements**

How should the communication board's user interface work?

- **Basic communication requirements**

Which basic communication problems should be addressed and how?

- **Other communication requirements**

What other wishes / functionalities are requested by patients, caretakers and professionals?

- **Back-end**

How can the back-end be designed most user-friendly for caretakers?

Hardware requirements

The most important aspect of the hardware is that it needs to be very solid. Patients suffering from PD tend to make unexpected movements and fall down often. The communication board needs to be able to take a hit without fall-over and/or hurting the patient. In addition, patients should be able to use the communication board while seated or laying down, preferably in a way that takes into account their tilted statute:

"I always get shivers from these kind of devices, the first thing that comes to mind is 'I hope it does not fall'. The device should absolutely not be fragile; it should be what we call 'hufterproof'. Patients manage to break everything around them." ⁹

"I picture a communication board as a very large TV screen that is placed in front of the patient on a stand" ¹⁰

"The position of PD patients should also be taken into account for the communication board. They are often crimped together and suffer from adhesions" ¹¹

Creating a foolproof communication board can be accomplished by creating a solid stand for the screen that does not tip over easily and by mounting a rubber band all around the screen to prevent it from breaking and / or hurting the patient should it fall on top of him or her. Although the latter might seem an unusual requirement, PD patients have been known, for example, to rip entire doors from their hinges during unsuccessful attempts to walk around on their own. Ensuring that the communication board is as foolproof as possible, is therefore of the utmost – if not life-saving – importance.

As noted in chapter 4, final stage PD patients often experience visual problems, ranging from unclear vision to misplaced vision and the inability to see objects in correct depth. The screen of the device should therefore be quite big. The screen of an iPad or other tablet will not be sufficiently large enough for the end-user to clearly see the screen - let alone the icons or texts on the screen. The suggested size of the screen is 40 inches (101,6 cm) diagonally at a minimum.

⁹ T. De Haan – Parkinson consultant / specialist (St. Maartenshof, Groningen)

¹⁰ M. Westmaas – Physiotherapist / Scientific research coordinator (St. Maartenshof, Groningen)

¹¹ K. Kamphuis – Coordinator Parkinson section (St. Maartenshof, Groningen)

Due to the patients' limited motor skills, which may differ per patient, the hardware should allow for multiple forms of command that rely on the strengths of each individual user. If a patient has reasonable eye-hand coordination, the board should project large buttons on a touchscreen. If not, the board could use a camera that registers whether the patient moves his head up or down. Alternatively, large physical buttons – such as the controllers of the Wii console – could allow the patient to navigate through the communication board through hand movements. For those users with visual problems, the communication board should also contain speakers that speak out the items shown on the screen. These different input methods are necessary to address the limitations of different patients.

Tabel 4: Hardware requirements

Type of hardware	Requirements
General	Indestructible Solid stand Rubber padded edge Manageable from bed/chair
Screen size	Large > 40 inches
Input/output methods	Touch screen Camera Handheld controllers Speakers

General software requirements – front-end

As mentioned before, each patient is different and has idiosyncratic limitations. The software of the communication board should be designed in a flexible manner so that it can be adjusted to the needs and limitations of the individual patient. Indeed, experts note that one of the main limitations of existing devices is that they are not adjustable to individual patients:

“In the past we used those kind of touch-to-speak devices by aphasia patients, but the adjustability remains very limited” .. “I think patients could benefit from a communication device, but not from the currently available supporting devices. The cognition of patients becomes more of a problem over time and current devices do not adapt to this.”¹²

Patients’ abilities and limitations differ from day to day as well, as noted by one of the caretakers:

“On a good day Patient B is still able to drink his coffee himself and this is something he prefers. You need to hand him the cup directly in his hands because if you hold it in front of him he tries to grasp it, but his hand is 30 centimeters off. You also need to stay with him to address unexpected movements.”¹³

In practice, this means that if a patient has reasonable sight, for example, the communication board does not need high contrast icons and extreme large icons. If the patient suffers from hallucinations, on the other hand, the colors and the interface should be as simple as possible to ensure visibility. Depending on the patient, caretakers or professionals should therefore be able to simply change settings to adapt the communication board to the patient. This is particularly relevant given that advanced PD patients often end up in hospitals or nursing homes. Adaptability of the communication board would allow the staff of such institutions to use the same communication device for multiple patients. Such settings might also include a range that could be adjusted to the extent that the individual patient has a good or a bad day. As such, the communication board might challenge patients on good days whereas it turns to easier settings on bad days to prevent patient frustration.

¹² C. Quak – Speech therapist (Pieter van Foreest behandelcentrum, Westland)

¹³ Caretaker B – Caretaker of patient B (Naaldwijk)

In terms of software speed, almost every interviewee mentioned the same important aspect of the communication software: it needs to be slow. Patients suffering from PD seem unresponsive sometimes, but in reality they process information and formulate their outputs in a very slow manner. This is comparable to the sensation of running under water. When communicating with patients, the audience needs to give them sufficient time and should not ask another question or assignment directly if they seem unresponsive.

*"You see that always when somebody asks a patient if he would like some coffee. They ask immediately if they have milk or sugar in their coffee and if they would like a biscuit with it. That's 4 questions for the patient, 3 to many."*¹⁴

Patients suffering from PD have trouble continuing a conversation and need to be reminded constantly of the activity at hand. Patients also tend to doze off. It takes them an enormous amount of energy to focus and to respond to questions. This not only happens to advanced PD patients, but also to those in the first phases. During my attendance of the Regional Parkinson Meetings, I met with Parkinson patients who would suddenly become tired at the meetings and who apologized for this beforehand. As noted by one expert:

*"A patient thinks slowly, communicates slowly and processes information slowly. If the patient receives too much input simultaneously, things go wrong. Make sure the communication board addresses only one thing at a time."*¹⁵

In order to address these problems, the communication board needs to be very slow in everything it does, it should minimize the number of actions and questions needed to operate the device, and it should repeat commands continuously. The software does not need to be flashy and fancy. Options should present themselves slowly and the software should give the patient plenty of time to respond. An added advantage of such slow and repetitive software might be that it could force caretakers to communicate at a slower pace as well. Caretakers tend to interpret what the patient is thinking for them and ask too many questions simultaneously. If the communication board functions slowly, this might condition caretakers to adapt their communication style. The saying "Less is

¹⁴ K. Kamphuis – Coordinator Parkinson section (St. Maartenshof, Groningen)

¹⁵ T. De Haan – Parkinson consultant / specialist (St. Maartenshof, Groningen)

more” really applies to PD patients, and as such, the communication board could help instill this knowledge in their caretakers as well.

Caretakers and experts that know the patient very well, know how to get the patient’s attention. Examples are putting on some music, moving the patient’s arms, and really addressing the patient when trying to communicate something or when trying to get the patient to do something like eating or standing-up.¹⁶ On the communication board, getting the patient’s attention could be accomplished by implementing some sort of trigger. This function could be different for each patient and could consist of playing a musical tune, video or picture pop-ups. This trigger should start automatically when the system loads the patient’s personal preferences so that the communication board immediately attracts the patient’s attention. In addition, such a trigger stimulates the degree of alertness needed for the patient to interact with the communication board. Indeed, as noted by several respondents:

“Attention is one thing, but you have to boost the alertness somehow. If the alertness is not sufficiently high enough, the task at hand will not be done or executed properly.”¹⁷

“I need to be reminded on the task I was doing. It is difficult to stay focused.”¹⁸

If a patient does not respond to a question or an action, the software should give the patient a reminder or an alternative for responding. This could trigger the patient’s alertness.

Navigation through the different sections of the communication board should be possible using all the different input techniques mentioned in the hardware section. Given that life is not easy for final stage PD patients and that these patients are unable to execute the most basic tasks, care should be taken to design a communication board that can be managed easily and intuitively so that it does not cause new or extra disappointments for the patient. One concern that the experts have with regard to the communication board is that it might be too difficult to handle:

¹⁶ E. Komdeur – Occupational therapist (Pieter van Foreest behandelcentrum, Westland)

¹⁷ E. Komdeur – Occupational therapist (Pieter van Foreest behandelcentrum, Westland)

¹⁸ Patient A (Haarlem)

“Cognition becomes more and more a problem when the disease progresses. Handling a supportive device often proves very difficult for advanced PD patients”¹⁹

The software could address this problem by implementing very simple navigation for the patient on the basis of large icons and/or photos. In addition, the software could be programmed to always return to the dashboard when it has not received input for a certain amount of time. The manual operation of the device itself should not cause the patient any frustration. As noted by one expert:

“I don’t use existing supporting devices with patients in a later phase. Usually they can’t operate the devices and it is frustrating for them to see that they need somebody else to use the device for them.”²⁰

Given that hand-eye coordination is very difficult for most patients, the software should be designed in a ‘forgiving’ manner. This means that if a patient sees a button, tries to touch it, but misses it, the software should still try to interpret what the patient was trying to do. Extending the boundaries of the button beyond the icons and leaving a lot of room in between the buttons might achieve this. There are limits to this strategy of course, but this feature might enable the patient to use the board by himself.

In terms of *front-end settings*, the communication board itself should not contain a lot of menus and choices for the patient and the caretaker. Although caretakers should be able to pick from a wide range of functions, an overload of information could discard the benefits of the communication board for the patient. This means that the front-end of the software should display the necessary functions for an individual patient only. This prevents that the patient gets stuck in the system. In addition, the communication board needs to have a clearly distinguished front-end and back-end. Making such a clear distinction is important to ensure that the patient cannot adjust settings by accident and get stuck in this part of the communication board.

¹⁹ C. Quak – Speech therapist (Pieter van Foreest behandelcentrum, Westland)

²⁰ C. Quak – Speech therapist (Pieter van Foreest behandelcentrum, Westland)

Tabel 5: General Software requirements

Software	Requirements
Configuration	Adjustable (by caretaker) Range of settings for individual patient
Speed	Slow Repetitive
Navigation	Various input styles Intuitive and clear Forgiving
Front-end settings	Simple Limited number of functions Constricted front-end

Basic communication requirements

The previous section addressed the general software requirements of the communication board to allow patients to use the board. These requirements are, however, only for communicating with the device and focus on input, the processing of information, and navigation. But what actual functions should the board should contain?

The primary function of the communication board is 'basic communication'. This module allows a patient to communicate the most basic things that confront him or her on a daily basis. In this sense, one may think of activities such as eating, drinking, using the bathroom, bathing and grooming, and sleeping. Currently, final stage PD patients are completely dependent on caretakers to meet their daily needs. If nobody gives the patient a drink, for example, he or she will not drink. The inability to express their needs increases patients' dependency on the 'whims' of their caretakers and may cause frustration and even bodily harm. Imagine, for example, when caretakers fail to notice

from a patient's face that he or she needs to go to the bathroom, or when a patient cannot find the words to communicate this. In such cases, the patient may end up trying to go by him- or herself and fall out of bed in the process. Alternatively, patients may end up covered in excrement and urine, which, needless to say, has a negative effect on patients' self-esteem and may lead to infections. The communication board could allow patients to express such basic needs.

Towards this end, the basic communication function depends on the use of categorized communication buttons marked by text or icons. A picture of a glass of water or a button that spells 'Drink', for example, allows the patient to communicate that they are thirsty. Based on the preferences of the patient, the appearance and size of these icons and texts should differ. As noted by one expert, for example, *"Icons work pretty well, but there are some patients from a different generation that do not recognize the meaning of icons. We might think it is convenient, but some patients just don't get them."*²¹ An important aspect that needs to be taken into account here is how the communication board addresses the patient. Most patients are educated persons and dislike being treated as a child. They wish to be taken seriously. The text or icons should be simple, but not childish. The communication board should be a supportive device that engages patients' use to express themselves.

A second function of the board is to enable 'pain communication'. Patients are engaged in a constant battle with their body and brain. When caretakers have experience with the patient, they can usually read from the patient's face or understand from their mumblings that something is wrong. Nevertheless, as noted by one of the caretakers: *"It is hard to find out exactly what Patient B is feeling. Because I see him on day-to-day basis, I can tell when something is wrong, but it is difficult finding out if he is in pain and where."*²² Physical and communicative limitations make it very difficult for patients to clearly indicate whether or where they suffer from physical inconveniences and pains. Needless to say, this could potentially lead to unnecessary suffering and life-threatening situations, as the patient may be unable to receive medical attention in time. Caretaker B provides a clear example of this:

²¹ G. Eppink – Spiritual chaplain (St. Maartenshof, Groningen)

²² Caretaker B – Caretaker of patient B (Naaldwijk)

“Patient B hit his toe last summer, which led to an infection. A combination of not addressing the infection on time on time and treating the infection with the wrong kind of antibiotic, put Patient B in the hospital for weeks fighting for his life.” ²³

A very important function of the communication board is therefore that it should give the patient the possibility to let the caretaker know that he/she is in pain (e.g. a headache) and how severe the pain is. The communication board can achieve this by building on the VidaTak example discussed in chapter 4, which allows the patient to point out pain on a sketch of a human body and to indicate how severe this pain is. The communication board should contain a similar technique to allow patients to indicate where they suffer from pain. This could be accomplished by providing multiple techniques to point out a region of the human body, such as an outline of the human body, a photograph of the patient, or text buttons or icons that can be managed through different input methods. The main input method will be the touchscreen, but if a patient lacks hand-eye coordination, physical buttons could be used. As such, it should be possible to identify the source of the pain through multiple paths. In addition, a simple scale could be added in numbers and images to allow the patient to indicate the amount of pain he or she experiences

Next to basic communication and pain communication, a third important communicative limitation for patients is that they are unable to express feelings. This is not only due to their limited ability to express themselves verbally, but also due to their lack of facial mimic. As noted by one expert: *“It is very difficult that patients have little to no mimic. Otherwise you could guess what they are feeling by looking at them”*.²⁴ Caretaker A agrees that it has become more difficult to communicate with her husband: *“Reading body language gets more difficult. Sometimes I ask “are you mad”, but then Patient A doesn’t know what I’m talking about because nothing is the matter”*.²⁵

Nevertheless, it is very important for patients to be able to express such feelings and their general state of mind, as they tend to get down and depressed. They often feel trapped in their own bodies and are unable to clearly communicate this to the people around them. Were they able to do so, this could motivate their caretakers to address these feelings through the organization of an outing or other types of activities that the

²³ Caretaker B – Caretaker of patient B (Naaldwijk)

²⁴ C. Quak – Speech therapist (Pieter van Foreest behandelcentrum, Westland)

²⁵ Caretaker A – Caretaker of patient A (PD patient)

patient enjoys. Another feeling that many final stage PD patients experience once the disease progresses is fear due to hallucinations. If patients were able to express such fear, this might enable the caretaker to take it away. Lastly, the inability of patients to express their feelings also inhibits them from interacting in a meaningful manner with the people they love. Being able to express basic feelings such love and momentary happiness might benefit not only the patient but may return some sense of closeness and intimacy to caretakers as well.

Towards these ends, the 'emotional communication' function should enable the patient to express their current feelings, such as happiness, love, feeling down, worrying, depression, or anger. This information could enable the caretaker to start a conversation to address the feeling at hand. Once again, flexibility and the possibility to use various input methods should guide implementation of this function. Depending on the patients' preferences, the communication board could use icons or text, songs or tunes that convey emotions, or photos or other types of pictures to allow the patient to express him- or herself.

Lastly, final stage PD patients often suffer from Parkinson dementia. This type of dementia is different from regular dementia, but similar aspects are: not recognizing surroundings, not knowing how they ended up where they are, and not being able to find the words they want to say. In the patient's mind, things may make sense whilst the audience may only hear mumbling. Therefore, the communication board should provide tools to help patients identify the subjects that they are thinking about. This could be accomplished by simple question lists with yes / no responses or something more comprehensive like images of general items. Recently, an app has been developed for patients suffering from aphasia by professor Desain of Nijmegen University that departs from word clouds. Some functions of this app could perhaps be implemented in the communication board.

A final function of the communication board could be to provide speech support. Several types of features could accomplish this. A first feature could simply remind the patient to speak up or to speak more slowly. By telling the patient to speak on different levels, the patient has to think more about speaking, which results in better pronunciation and sentence formation.²⁶ Alternatively, such a feature could remind

²⁶ C. Quak – Speech therapist (Pieter van Foreest behandelcentrum, Westland)

patients with abundant saliva to swallow. According to the European Parkinson's Disease Association, 50 to 80 per cent of PD patients have problems with saliva and drooling. By reminding these patients at certain intervals to swallow, communication could improve. In addition, this feature could mimic elements of the above-mentioned SpeechEasy and SpeechVive devices. This means that the communication board would provide soft background sounds or amplify the speech of the patient on a different speed when the patients starts talking. Nevertheless, care should be taken to only enable this feature for patients that can still benefit from it as such features may impede speech of patients with more advanced speech problems.

In addition, a speech therapist mentioned that integrated speech exercises could even help improve the patient's speech.²⁷ Such a more advanced feature could provide exercises that trigger the patient's brain not to 'work on autopilot'. Such a feature should target the segment of the brain that is most influenced by the disease. Exercises that trigger the brain to work outside its usual pathways improve functioning. A good example of this occurs with PD patients in earlier phases in the disease. Even when patients can hardly walk, they can walk up and down the stairs almost effortlessly because this action triggers a different, non-autopilot, part of the brain²⁸. This has to do with the aspect of 'thinking about their actions' that triggers a different section of the brain. This 'making the patient about their actions' strategy is implemented in other ATP's for PD patients as well, such as the specialised Parkinson walker which projects a laser line on the floor that triggers a different part of the patient's brain while walking. The communication board could contain similar types of exercises that trigger different parts of the patient's brain while he or she tries to speak.

²⁷ C. Quak – Speech therapist (Pieter van Foreest behandelcentrum, Westland)

²⁸ The following video provides an excellent example: <https://youtu.be/Lc-8gzTDD5I>

Tabel 6: Software - Communication requirements

Function	Requirements
Basic communication	Icons or text Simple but not childish
Pain communication	Outline of the human body or buttons Pain scale
Emotional communication	Icons or text Songs/tunes that convey emotions Photos or pictures that convey emotions
Communicating with dementia	List of questions with yes / no responses List Word cloud
Speech support	Reminders to speak up / slowly Reminders to swallow Soft background noises Speech amplification Non-autopilot speech exercises

Other communication requirements

During the interviews it became clear that, even though communication about daily tasks is difficult, most patients miss the ability to communicate about other things. They miss connecting with their audiences over stories from the past, such as holidays or other pleasant experiences. Patients tend to enjoy talking about more than just the things they need to address their most urgent needs. Caretakers and professionals also

mentioned other things that could be included in the communication board to improve their treatment of advanced PD patients. All these wishes are bundled in this section.

The wish to communicate about 'other' items and not only the practical functions became very clear during the interviews with the experts as well as the interviews with the patients and caretakers.

"Patients wants a different type of contact in the final phase of the disease. They do not want to talk just about a visitor that dropped by or about some bird outside of their window. Patients want to talk about things that matter and that are important to them, such as how they would like to see their loved ones looked after when they pass away" ²⁹

Supporting the patient in a way to start a conversation about things that are important matters. Such conversations would help patients feel respected and taken seriously. The communication board may support patients to have such meaningful discussions through the provision of categories of words or pictures that might help patients convey to their audience what they would like to talk about. Caretakers or family members could also use these categories to figure out what the patient would like to talk about.

When patients still live at home, a spouse or relative usually knows stories from the past to talk about. However, if some old friend or a distant relative comes to visit, it could be difficult to start a conversation. The same goes for personnel in nursing homes. Implementation of personal photo albums and perhaps a timeline containing important life events could remedy this by make the communication board more personal. Indeed, as noted by one expert: *"Talking about recognizable things, pictures from the house they grew up in, the family, their profession, etc. are things that work very well in my daily job."* ³⁰ The timeline could mention, for example, that a patient bought a house 20 years ago and thereby set a topic for conversation. A caretaker (or perhaps the patient himself) could slide or navigate through the timeline to talk about events. Of course, it should be possible to add items and upload photos to the timeline in an ease manner.

Next to forming conversation starters, these features could also have an entertainment function. Everybody likes to look at holiday or wedding pictures. PD Patients are no different, and given that they have a lot of time on their hands and always find

²⁹ C. Quak – Speech therapist (Pieter van Foreest behandelcentrum, Westland)

³⁰ G. Eppink – Spiritual chaplain (St. Maartenshof, Groningen)

themselves in the same environment, looking through photo albums might improve their day a little bit. Like the time-line, photos could also form a good conversation starter for a caretaker or visitor. Caretakers could simply upload photo albums to the communication board for the patient to view. The photos could rotate automatically or the patient could be in control through the use of the touchscreen or physical buttons. A sliding movement is properly not possible for PD patients, but touching the left or right part of the screen might enable the patient to navigate through the pictures.

Other types of entertainment features could be added to the communication boards. PD patients often feel trapped in their bodies and are unable to partake in activities. As noted by one caretaker: *"I have no idea how to give Patient B something to do to pass the time. I have tried toys, DVD's and games but it is difficult to find a proper activity for him to enjoy the day with instead of counting the hours before he can go to bed again."*³¹ The added use of the communication board in this regard is that it would enable the entertainment to be adapted to the speed and limitations of the patient. Lowering the speed of news broadcasts and audiobooks, for example, might enable the patient to better understand what is being said.

Given that the communication board has a large screen, it may also enable patients to watch online television and movies. The screen may also be of use for the screening of instruction videos. The condition and energy of PD patients differs from hour to hour and – knowing from personal experience – patients are not always able to do exercises at the time a professional, such as a speech therapist or physiotherapist, comes by. Therefore, it would be ideal if such professionals could load exercises into the communication board. A caretaker or nurse could start these exercises when the patient is in a good mood and / or feels up to them.

³¹ Caretaker B – Caretaker of patient B (PD patient)

Tabel 7: Software - Other requirements / wishes

Function	Requirements
Start conversations	Provide lists of words Upload personal photos and videos Personalized timeline
Entertainment	Upload personal photos and videos Adjusted settings for audiobooks, etc. Television settings
Exercises	Integrate exercise modules

Back-end

The back-end contains the settings of the communication board. These settings are linked to patient profiles so as to adjust the front-end to the limitations and requirements of individual patients. In addition, patient profiles contain the pictures, videos, songs and exercises that are applicable to him or her. The back-end should provide options to upload new materials to the existing profiles as well as the option to create a new patient profile. Although the back-end does not need to be as simple as the front-end, it should still be designed in an intuitive manner. This is the case because if the caretaker is unable to manage the back-end, the patient will not get to use the communication board. It should be taken into account that many caretakers or family members possess only basic or limited computer skills. The back-end should be designed so that experience with the communication board is not necessary to manage the individual patient's settings.

Next to their inability to manage the communication board, caretakers' unwillingness to use it may form an important obstacle. Such unwillingness can be traced back to the workload of healthcare personnel. Nursing home staff often work by the hour and provide the necessary support, such as showering, shaving and getting the patient dressed

for the day. Their perception is different than the perception of the patient. They have a task to do and do not always have the time to communicate properly with the patient.

"They often think that they do not have the time to talk to the patient. Even though it is often just a very small amount of work. Just sit down with the patient for 5 minutes to see what is on their mind" ³²

"You need the corporation of the healthcare employee. They often say they are too busy. We need to find a solution that they actually use the device and don't leave it standing in a corner. It should be a part of their work process." ³³

"You need the professional caretaker, but they often say that they are too busy. We should find a solution to prevent them for not using the device. The communication board should be a part of their work flow." ³⁴

"One of the major problems I am facing with my work is that everything is rushed. My colleagues think they have no time to talk to the patient when is it often just a couple of minutes listening to the patient to remove their worries or frustrations." ³⁵

Addressing the professional caretaker will be quite a challenge, as they need to see the added value of the communication board. As noted by the respondents, the best way to tackle this problem is to integrate the communication board in the personnel's workflow. At the very least, it should be possible to change between individual patient settings in only one or two steps. This would ensure that the caretaker could integrate the communication board within his or her routine without much extra effort. In addition, the communication board should be introduced by connecting it to problems that create a lot of extra work for caretakers. The choice between using the communication board to understand whether their patients need to go to the bathroom, or cleaning up the patient and changing his or her sheets, for example, seems an easy one. The communication board should be 'sold' as a time-saver rather than as an extra task.

³² P. Ossenbrug – Homecare employee (Pallia Zorgbureau, 's-Gravenzande)

³³ K. Kamphuis – PD coordinator (St. Maartenshof, Groningen)

³⁴ K. Kamphuis – PD coordinator (St. Maartenshof, Groningen)

³⁵ P. Ossenbrug – Homecare employee (Pallia Zorgbureau, 's-Gravenzande)

Tabel 8: Back-end

Function	Requirements
Back-end settings	Basic and intuitive

Chapter 6: Prototype

The prototype's design

Development of the prototype focused on the following segments: the hardware of the communication board, the front-end software running on the hardware and the back-end software for the caretaker / professional to make adjustments for different patients. This chapter discusses the prototype's development in detail and specifies the engineering decisions that were made.

Hardware

During the research it became clear that the screen of the communication board should be very large, preferably with a screen of 40 to 46 inches in diameter. The prototype consists of a very large 55-inch StarScreen to test whether bigger is better or whether too large a screen interferes with the patient's ability to manage the communication board. The screen is a 'dumb screen', meaning that it runs firmware but no additional software. The screen contains a full-HD Sharp television in an iron casing with an extra glass plate on the front. In the screen's corners, multiple cameras identify when and where the user touches the screen.



Figuur 1: StarScreen 55 inch full HD touchscreen

As discussed in chapter 5, the communication board should be portable and it should be designed as indestructible as possible. The screen and its iron casing combined weigh 67 kg. Since the screen is so heavy, a customized stand had to be built to support the weight of the screen and to allow for the screen's (basic) portability by the caretaker. The stand consists of an iron table that has been welded to support the massive screen.



Figuur 2: Table welded with 2 rotating carrying bars and wheels



Figuur 3: Screen is mounted securely using 22 bolts, back is height adjustable

The screen can now be attached to the table using 22 bolts. This secure attachment, combined with the screen's weight, ensures stability of the communication board, as it will be virtually impossible for the patient to topple the screen over.³⁶ In addition, the stand has also been customized with wheels in order to create a moveable table. This allows caretakers to wheel the screen to the patient and to put it over a wheelchair or bed.

Given that the screen has no internal computer to run the communication board, this had to be added externally. After doing some very basic research, I decided to use a Raspberry Pi 2 motherboard, basic casing, and a memory card of 8GB. Putting these items together created a fully functional computer the size of a credit card. As such, it could be attached to the communication board screen without adding extra weight or bulk. After a first test, it turned out that this specific type of touchscreen works perfectly on Linux (the operating system of the Raspberry Pi), but that the touch screen drivers do not support the architecture of the Raspberry Pi (ARM). Replacement of the Raspberry Pi by another small bare bone computer (JetWay) solved this problem.

The JetWay contains a small hard-drive and has been fitted with internal handmade cables. It runs on Windows 7. On this machine, the installation of the touchscreen drivers works flawlessly. Although it is a bit larger than the Raspberry Pi, the JetWay can still be mounted to the communication board without adding extra weight or bulk. The JetWay has been attached to the stand and connected to the screen using a DVI cable and an USB cable to communicate with the touch functionality. In the future, alternative input methods, such as physical buttons and motion and voice activated hardware, may be connected to the JetWay. The prototype does not contain such alternative input functions, as the touchscreen function is the most important input function that needs to be tested.

³⁶ Due to the fact that the prototype is developed for testing purposes only, meaning that somebody always monitors the patient's use of the communication board, the screen itself has not been customized to ensure protection of the patient. If the prototype were to be developed further, a rubber band should be mounted on the edge of the screen.



Figuur 4: JetWay barebone computer used for the prototype



Figuur 5: Computer is mounted under the table and connected using Wifi

General software

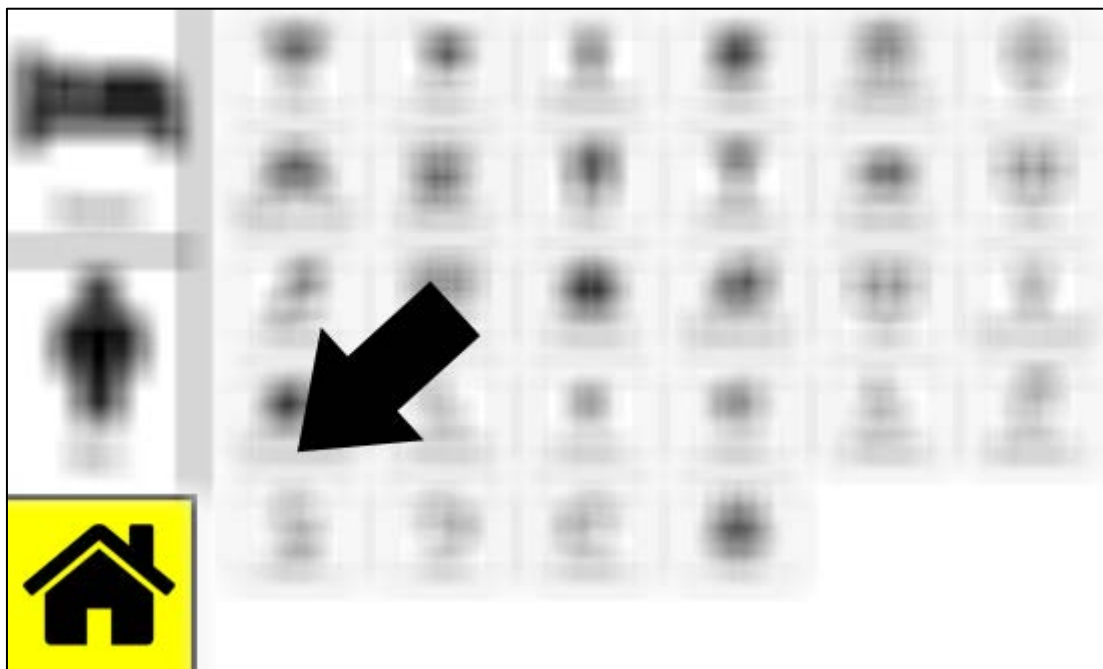
The general software that runs the prototype consists of a web application. The communication board starts up in kiosk mode without any menus or scrollbars – thereby ensuring the board’s simple manageability by the user and preventing prevent (accidental) tampering with menus and settings. The added value of the web application is that it is relatively easy to create different versions of the user interface by using different Cascading Style Sheets. This allows for the quick adaption of the communication board to support the needs of different patients. Two disadvantages of the web application are that it requires a constant Internet connection and that it could be slower than internal software. For the prototype, this has been solved by installing a local webserver on the communication board itself – meaning that access to the Internet is only required to update the settings and profile of a patient. Future development of the communication board should investigate internal software alternatives in more detail, as application of a software language might be preferable to a web application.



Figuur 6: The main screen of the communication board

As discussed in chapter 2, the two patients, who provided data on the communication board’s requirements and limitations, will test the prototype. Given this limited sample, the prototype has not been designed to be customizable to the needs and preferences of

individual patients.³⁷ Instead, the prototype user interface has been built as simple and clearly as possible using black and white icons with solid black corners. Each icon on the main screen also contains a description of the topic at hand.³⁸ To make the navigation as clear and intuitive as possible for a patient (and caretaker), each screen contains one 'home' button. In addition, this button is located in the same position on every screen. This allows the patient to return to the main screen with a single touch. The home button is designed to capture attention by its setting in the form of a high contrast color combination (yellow / black).



Figuur 7: The home button that is available on every screen

In order to ensure that the software is slow, the software has implemented delays in the JavaScript functions, such as the photo slider, to ensure that the patient has sufficient time to process information. The software has been designed to be repetitive through the implementation of confirmations and repeating questions / photos. This means that if a patient touches a photo depicting food, an additional question pops up asking the patient if he/she is hungry. In a similar vein, if the patient does not select a photo, the photo slider continues to repeat itself. Each feature is accessible from the main screen by using large icons. The icons are surrounded by a forgiving border, meaning that if a

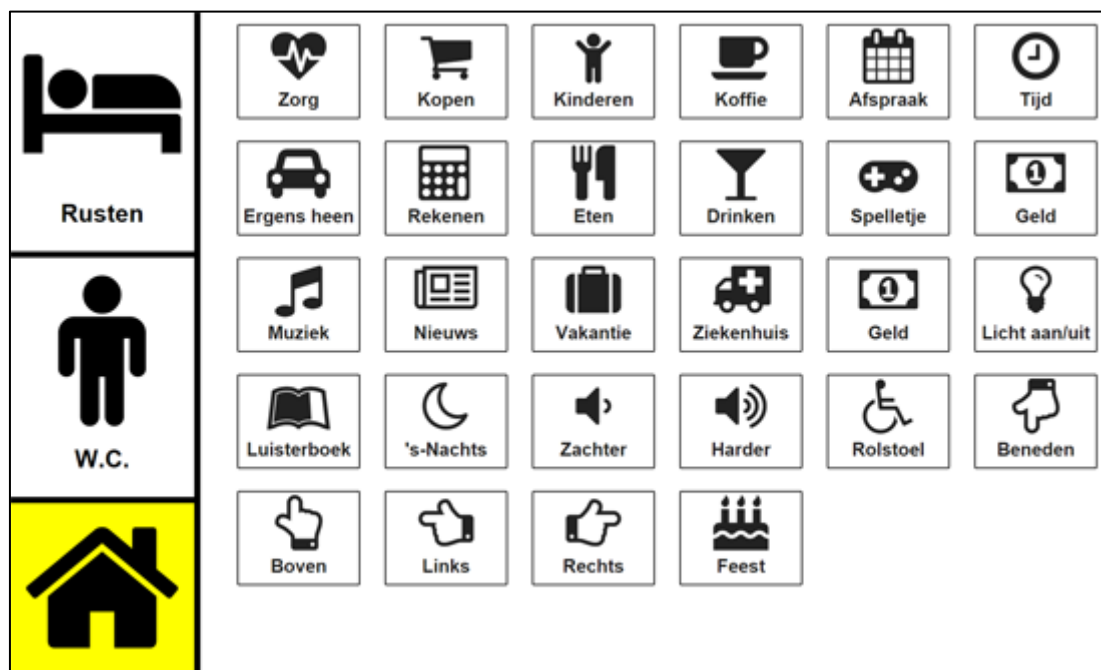
³⁷ This setting may be added to the interface of the prototype in a later development stage.

³⁸ In a later development stage, this description should only be made available to patients that are still able to read some texts to avoid creating frustration.

patients tries to touch an item but misses it, there is a margin on the outside of the border where the item still works.

Basic communication functions

Chapter 5 identified many possible features for the communication board. The prototype contains at least one feature for each segment of basic functions: basic communication, pain communication, emotional communication and communicating with dementia.³⁹ Although these features are not exhaustive, they are extensive enough to test whether the patient is able to use them to enhance his or her communication skills. The basic communication function consists of a folder ‘say it with icons’ that contains 28 icons pertaining to everyday activities and objects, such as ‘wheelchair’, ‘food’, ‘drinks’, ‘music’, ‘outside’. These icons allow the patient to communicate basic requests or needs by selecting relevant topics.



Figuur 8: Basic communication with icons

In addition to the icon screen, it will also be possible for patients that do not see or recognize the icons to express their basic communication needs through photos. This feature, called ‘say it with photo’s’, consists of photos in a slow slider. The patient only

³⁹ Speech support is an advanced segment of features that may be added to the final communication board but that were not included in the prototype.

needs to touch the screen when the relevant photo passes. The photos vary from a bottle of water (to drink) or a forest (to go outside).



Figuur 9: A photo from the photo slider

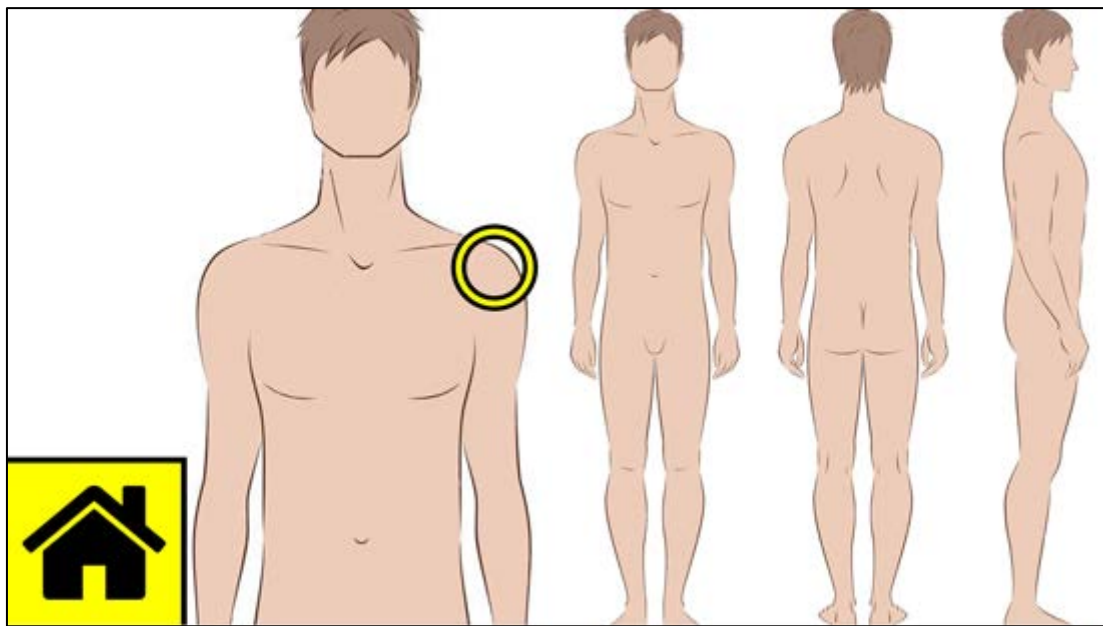
Once the patient sees the image, a touch somewhere on the screen results in the pop-up of a confirmation question. This feature allows the patient to return to the home screen in case of a mistake.

Wilt u iets drinken?	
Ja	Nee

A yellow square with a black house icon, located in the bottom-left corner of the 'Ja' button.

Figuur 10: Confirmation once a patient touches the screen

For pain communication, a screen has been developed that depicts outlines of a human body. On this screen, the patient can touch the area where he or she is in pain. A black and yellow circle highlights the area touched by the patient. The patient can touch multiple sections if needed. For the prototype, the focus lays on identifying the location of the pain only. The severity of pain is currently not implemented in the board, but future development of the communication board should focus on the development of a pain scale as well.



Figuur 11: Pain communication

For emotional communication, a basic screen has been developed that allows the patient to express his or her feelings in an easy manner. This is accomplished through the creation of three general buttons (Happy, Neutral, Sad). Touching one of these buttons switches the screen to several connected feelings. For the prototype, those feelings are depicted as icons with text only. For the future communication board, photos and songs / tunes could be used as well. In the prototype, the feeling icon turns yellow when selected by the patient. As seen on the screenshot below, the patient may also select multiple feelings.



Figuur 12: Feeling communication

In order to communicate with patients suffering from Parkinson dementia, a questionnaire has been set up to identify the topic that the patient would like to talk about. By providing the patient with mostly yes / no questions, it is possible to identify many topics. Future development could add a more advanced 'word cloud' system so as to better identify communication topics based on association.



Figuur 13: Questionnaire to identify topic

Other communication functions

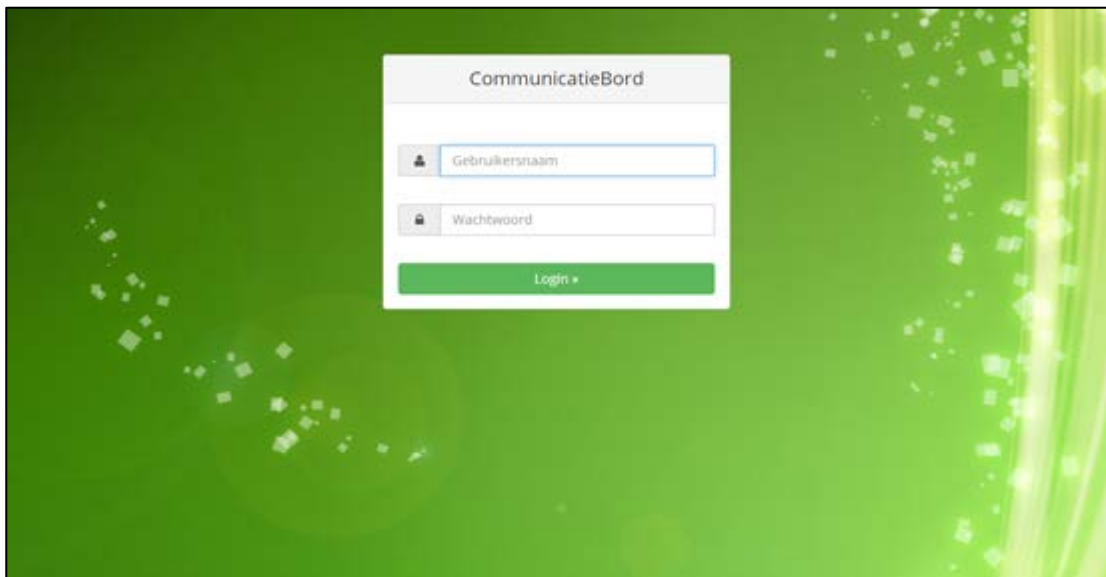
As discussed in chapter 5, patients and caretakers indicated that the communication board might serve additional communication needs as well: start conversations, offer entertainment, and provide exercises. With regard to the need to start conversations, relatives and friends oftentimes do not know how to deal with PD patients that they do not see every day. Patients like to talk about shared experiences or interest or to reminisce about the past. For this type of communication, a personal timeline with photo albums has been implemented in the board. The idea is that visitors can use this function together with the patient to start a conversation on topics such a holiday that they once took together. The personal photo albums can also be used as a slideshow to entertain the patient. In addition, an entertainment page has been added that contains videos, such as from the patient's favorite bands or TV shows, which the patient can watch. The implementation of audio books and live television streams lay beyond the scope of the prototype, as doe the speech and physical exercises discussed in chapter 5.



Figuur 14: Timeline feature

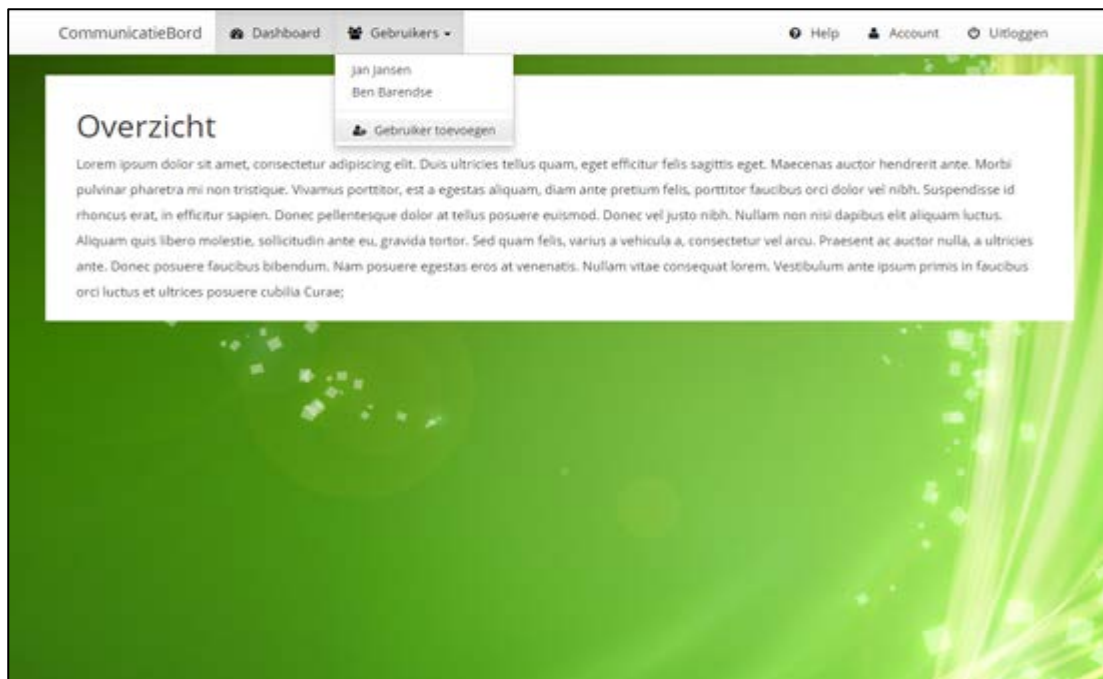
Back-end

A local installation of Apache and MySQL has been installed on the JetWay computer to set and upload patient profiles to the communication board. This database is combined with a web application at the Internet domain created for this study's prototype at: <http://www.communicatiebord.nl>. The domain name is chosen to ensure that caretakers can remember it easily. The web application allows caretakers that have access to a basic computer with Internet to manage the communication board settings for their patient. They do not have to install any additional software. The application is build using the CakePHP framework for stability and security and allows caretakers to log in using their own credentials.



Figuur 15: Back-end login screen

Once logged in the caretaker can add a new patient, or, in cases such as nursing homes, multiple patients. In addition, the web application allows for modification of the settings of existing patients.



Figuur 16: Dashboard for caretaker

For each patient, a number of settings can be modified. Based on the specific settings, the communication board loads a personalized style sheet for the patient. Currently, the backend supports the most basic settings only:

- A setting for gender that determines whether the outline of the human body under the 'i have pain' setting pertains to a male or female patient;
- A setting for general visibility that relates to image sizes;
- A setting for whether the patient suffers from hallucinations that relates to image contrasts and colors;
- A setting for whether the patient has saliva / swallowing problems that sets into motion pop-ups at frequent intervals reminding the patient to swallow.

The caretaker can also use this back-end application to upload videos and photos to a specific patient's profile.

The prototype's validation

It is virtually impossible to move final stage PD patients due to their physical limitations and psychological need for stability and predictability. This means that the prototype had to be brought to the patients for testing. Two added advantages are that this allows for the testing of the prototype: 1) by the patient, his direct caretakers, and regular healthcare professionals 2) in the environment for which the device designed. Including various types of end-users in the validation process ensures that the validation findings to do not apply to the single patient per se. Testing the prototype in a normal environment increases the chance that the validation process mimics the real usage of the communication board in everyday life. Appendix 2 provides an overview of the questions that form the basis for this validation exercise. The validation itself is divided to test the four prototype segments discussed above: hardware, software, improvement in communication, and back-end.



Figuur 17: Communication board is transported to test patient



Figuur 18: Complete setup for validation

Hardware

The first validation exercise tested the communication board's screen size in terms of manual manageability and visibility. The screen turned out to be too big for manual manageability as the patient was unable to physically reach all the screen's four corners (as depicted in the image on the next page). Nevertheless, the screen was big enough to ensure that the patient could see the entire screen. He was able to read the texts of the top icons and to identify the location of all the pictures and icons. A tradeoff appears to exist between manual manageability and visibility, with a bigger screen resulting in more visibility but less manual manageability. Future development of the communication board could experiment with smaller screen sizes to test if a slightly smaller screen results in a combination of the best of both worlds. Alternatively, the manual manageability of the screen could be improved by only locating icons on the lower half of the screen, where the patient is able to touch them, while ensuring that pop-up images and photos are displayed over the entirety of the screen for visibility purposes.



Figuur 19: Prototype validation by patient

In terms of manageability of the board itself, the image above shows that the communication board fits properly over a chair. An additional test with a wheelchair confirmed this finding. Since the iron table that supports the communication board is 1.45m wide, the device will also fit over a single bed of 80 or 90 cm wide.

Given final stage PD patients' power of destruction, due to their imbalances and clumsy movements, the prototype needed to be able to support the weight of a fully-grown male (100+ kg). For validation purposes, I tested this by hanging on the side and the front of the prototype, which did not tip over in the process.⁴⁰ This means that, in theory, a patient should be able to get up from his chair by using the communication board for support without causing direct accidents to him- or herself and / or the board. Future development of the communication board should nevertheless test this issue so as to ensure complete safety for the user.

Regarding the sensitivity of the touch screen, the patient was able to manage the touch screen without any force. This shows that the current settings of the prototype are sensitive enough to respond to the touch of a PD patient. If needed, these settings could

⁴⁰ To make the prototype adjustable for a patient, the support on the back of the screen exists of a single iron bar that can be set to numerous heights. This side has not been fully tested as to whether it supports the weight of an additional 100 kg. However, the back support is fitted with locking pins to securely mount the screen once the correct height is set, suggesting that this should cause no problems.

be further adjusted to add extra delays or to respond when the patient merely hovers over the screen. Future development of the communication board could allow for the adjustment of this setting according to the needs of the individual patient.

Software

In terms of speed, the communication board software starts automatically when the communication board boots up. Initial tests showed the software to be relatively stable and speedy. Initially, a development oversight resulted in JavaScript alert boxes popping up over the screen. The software required the patient to close these boxes before being able to continue using the board, which created confusion for the user. These ‘freezing’ issues have been addressed so that they no longer block the patient’s usage of the communication board. Besides this development oversight, the web application runs speedily, without any freezing or unwanted delays.

The main issue that came up during the validation of the general software is that the test patient found it very difficult to use the communication board and that it was virtually impossible to test to what extent the patient understood the logic of navigating the board. The test patient was able to return to the home screen on various occasions, but it was unclear if the patient was completely aware of the action or the response at the time. In a similar vein, the patient was able to identify and touch the icon for ‘pain communication’ but could not indicate on the next screen how he would communicate having a headache by pointing out specific areas on the body’s outline. These findings point towards a severe limitation to the communication board’s usefulness as it suggests that PD may impede patients in the final stage of the disease from operating even this most basic device.⁴¹ Given this limitation of the prototype, it was impossible to test the extent to which the patient found the board intuitive and forgiving.

Despite this problem with navigating the board, the patient did appear to enjoy practicing with the communication board and the board definitely interested him. The screen size combined with the brightness allowed the patient to properly see everything on the screen. The test patient was able to correctly identify the icons, texts and images. The picture slider works properly, but moves too quickly for the patient in

⁴¹ Since final stage PD patients’ bodies do not respond well to their brain’s signals, it is very difficult to actually lift an arm and point or touch an item while thinking about it. Indeed, one general symptom of the disease is that patients’ bodies are unable to execute the commands they wish to do.

its currents setting. Future development of the board should address this issue. In addition, it does not appear that the communication board confuses the patient, especially when operated together with a caretaker or healthcare professional. As such, the prototype scores well on the issues of user friendliness, visibility, simplicity, and speed.

Combined with the findings above, this suggests that although the test patient is currently unable to operate the device, he does enjoy the access to information that the board provides him with. Future development of the board should focus on testing to what extent the manageability function can be improved. It may be the case that the patient can be trained in using the communication board. The next step in the development process will therefore consist of organizing training sessions at regular intervals during which the patient can practice using the board. In addition, extra input methods will be added to the board to test whether pressing a button rather than touching the screen makes a difference in the patient's ability to navigate the board. When doing a separate test with the patient in pressing large physical buttons, the patient was able to make the connection, lift his hand and actually hit the button on command. This suggests room for improvement through alternative input methods.

Improvement in communication

The above findings have implications for the validation of the improvement in communication as well. Given that, at this point, the test patient is unable to use the board to express himself, the various communication methods could only be tested in a general manner. A first series of tests revealed that the 'say it with photo's' and the 'pain communication' sections were most clear to the patient. The photos are large enough for the patient to see, and, once the slide has been adjusted to a slower speed, the patient should be able to process this communication method rather well.

The 'say it with icons' section seems to work reasonably well. The amount of icons is too overwhelming for the test patient so this should be reduced in future development and / or adjusted to the individual patient. The same finding goes for the emotional communication section of the board. The basic feelings (happy, neutral and sad) work properly, but the amount of sub-feelings overwhelms the patient. In combination with a caretaker, however, these sub-feelings work quite well. They allow the caretaker to better identify the types of feelings that the patient may experience by naming them and

selecting them if the patient agrees. In a similar vein, the various steps in the 'PD dementia questionnaire' allow the caretaker to walk the patient through various topics of discussion. The caretaker was thus able to use the board as a communication starter during these initial tests.

Most importantly, both the test patient and the caretaker responded positively to the board's entertainment function, such as the time line slider showing photos and stories from the past. During the testing phase, it became clear that both the direct caretaker and other volunteers that visit the patient turned to board enthusiastically as a means to communicate with the patient. An added advantage of the fact that the prototype runs in a web browser, is that the caretaker and volunteers used the system to read the news together with the patient and to look up places around the world using Google Earth and its street view function. These kinds of usages, even if unplanned, improved the patient's quality of life, which is the entire purpose of this research. As such, an initial finding is that the communication board functions very well as a means to entertain the patient. Indeed, this function might be one of the most important ways in which the communication board can bring a little bit of happiness to final stage PD patients.

Back-end

Validation tests showed that the principal caretaker took to the communication board better than expected. Even though this caretaker's Internet experience is mainly limited to Internet banking and using e-mail, she was able to log in, add a patient and edit the settings for the patient. The back-end required little explanation and the caretaker was able to operate the website by herself. Dragging and dropping photos to create photo albums was also not a problem. In terms of intuitiveness, the back-end thus functions rather well.

Although the communication board did not improve basic communication with the patient directly, the caretaker did enjoy using the board as a means to connect with the patient. After the first week of tests, the caretaker used the communication board several times to practice with the patient (reading out the icons) and to entertain the patient. Even though the communication board does not allow the patient to communicate better by himself, these initial tests do suggest that the prototype enables the patient to engage in more meaningful forms of communication with the people around him.

Chapter 7: Discussion and conclusion

This study departed from the human computer interaction perspective (HCI) to identify communication needs and the cognitive, perceptual, and motor limitations of final stage PD patients as a first step towards developing a communication board that specifically targets this group of patients and thereby contributes to their quality of life. Towards this end, this study has integrated the literature on human computer technology with the more applied literature on PD as a means to evaluate existing communicative devices. In addition, interviews with patients, caretakers and healthcare professionals were held to identify the problems, needs and wishes of this select group of patients. The interviews provided a clear picture of the requirements for final stage PD patients and their caretakers: a slow and simple device that addresses both basic and more advanced communicative needs for people that are trapped inside their bodies.

Given that no appropriate communication tools exist to support patients during the last stage of their lives, this study developed a prototype to address these patients' communicative needs. Despite attempts to create an intuitive and simple communication board, the development process was hampered by PD's effect on patients' ability to process information and to operate devices. As a consequence, this first prototype cannot be called an outright success in terms of improving basic communication – especially on the part of the patient. Nevertheless, the validation tests have shown that the prototype did contribute to communication between patient and caretakers as long as the caretaker used the device to initiate conversations and to entertain the patient. As such, this research has set a small step in the direction of improving final stage PD patients' lives through the development of a communication board.

This study's main limitation is that the prototype was developed and tested with use of a convenience sample of two patients. Although this declines the reliability of the findings and the validation exercise, as it is unclear to what extent these patients are representative for PD patients more generally, selection of these two patients was the most ethically appropriate research strategy. This is the case because many advanced PD patients are confused and scared, and might not take well to strangers approaching them with complex conceptual questions that require a lot of imagination and mental clarity. One main advantage of the convenience sample was that the prototype could be

validated in a natural environment without putting extra stress on the patient. Future research into the optimization of this communication board could work around this technical limitation by implementing the communication board in the daily life of a broader sample of patients, such as in a nursing home, and by unobtrusively observing patients' and caretakers' use of the board.

Findings

In terms of this study's main research question, the following answer can be given:

"What is the best way to communicate with advanced Parkinson's Disease patients through the use of a digital communication board?"

This study has shown that PD, particularly through its limitations of cognitive, perceptual, and motor capabilities, hampers the patients' (cognitive) ability to manage a digital communication board. Nevertheless, the prototype's validation has shown that the patient under study nevertheless benefited from the communication board when operated by a caretaker. The communication board functions as a topic starter and has a clear entertainment function. This is particularly relevant given that the alternative is oftentimes that patients just lie in their beds and stare at the ceiling. As such, the best way to communicate with final stage PD patients is for patients to use the communication board together with a caretaker as a means to connect and pass the time together.

In terms of this study's sub-questions, the following answers apply:

"How can a Human-Computer Interaction approach be used to categorize user needs and limitations?"

The review of the HCI literature pointed out the relevance of focusing on various aspects of the design process, such as hardware requirements, general software requirements, and basic communication requirements. In addition, it pointed out the need to identify all the relevant stakeholders and to design both a front- and back-end system according to these stakeholders' needs and limitations. By identifying the main stakeholders – in this research the patient, the caretaker and the healthcare

professional – the main communicative limitations and needs could be identified through qualitative interviews.

"What are the communication-based limitations of advanced PD patients?"

The interviews revealed that PD patients generally have trouble communicating in the final phase of the disease. Even though not all patients are completely unable to speak at the end of their lives, most patients mumble and have trouble forming and finding words. When this is combined with Parkinson dementia, meaning that patients no longer recognize their surroundings and are prone to hallucinations, communication with patients becomes almost impossible. The lack of body mimic and the deterioration of bodily functions impedes communication even further, which in some cases results in a situation in which only direct caretakers and healthcare professionals, rather than relatives or friends, are able to communicate with the patient at the final stage of their lives. Needless to say, this does not contribute to the patients' quality of life.

"Which communication needs are not addressed on a day-to-day basis due to advanced PD patients' inability to communicate effectively? "

The interviews suggested that patients miss the ability to talk about things that actually matter to them the most, more so even than that they miss basic communication skills. Patients would like to be able to express their memories, feelings, and dreams. Caretakers, particularly in the case of relatives, noted that they missed meaningful communication with their loved ones. Healthcare professionals more generally indicated that communication limitations oftentimes stand in the way of providing better care. Given that caretakers have a full-time job in taking care of the patient, and that healthcare professionals have less and less time to spend with each patient, an effective and efficient communication board could ease and improve the provision of care.

"What are the current available types of communication devices and what are their strength and weaknesses?"

Chapter 4 discussed the different communication devices available on the market. Some of these devices might be suitable for certain patients, especially the ear devices, but they are unsuitable for final stage PD patients. The available 'communication boards'

are all too small and too limited, some are too complicated, and some are too childish. No communication device targets final stage PD patients specifically. Nevertheless, some of these devices' most useful elements have been implemented in the prototype, such as the icons, and the pain communication function.

"How can a communication board address advanced PD patients' communicative needs and which functions should it contain?"

On the basis of the interviews, the following functions were identified: basic communication, pain communication, emotional communication, communicating with dementia, and speech support. Nevertheless, and as discussed above, the test patient's inability to manage the communication board by himself suggests that exercising these functions may not become the final communication board's primary goal. The currently implemented functions did work quite when the caretaker or volunteer operated the board. Respondents also suggested more extensive communication functions, such as starting conversations, providing entertainment, and presenting audio or video exercises. The validation exercise suggests that these are the areas where the prototype has most potential. In addition, the interviews revealed that each patient has his or her own strengths and limitations even though patients tend to get similar symptoms. These individual needs and limitations are addressed by allowing the communication board to be customizable and configurable for each individual patient.

"How does the prototype communication board affect advanced PD patients' everyday communicative needs?"

The current version of the communication board is not suitable for supporting the patient on a day-to-day basis. More research, functionalities, and input methods should be implemented for the communication board to be used on a daily basis. As mentioned above, the prototype provides for a good starting point. It helps the patient to start a conversation and allows the patient, who has few other ways of being entertained, to watch some photos and videos.

The next steps and implications of this research

During the validation phase of the prototype, it became very clear that the development of a communication board for final stage PD patients is still in its infancy. Given the

enormous limitations of PD patients, future endeavors should focus on whether management of the board improves with training and / or alternative input functions. Despite these limitations, the test patient responded well to the communication board. Even though the screen was a bit too large and the patient was not able to control the features by himself, the prototype has proven itself to be a valuable communication starter. The main priority of this research was enabling a PD patient to communicate better and to express his or her needs and wishes and to improve quality of life. This latter aim appears to have been achieved at least partially.

The findings of this study can likely be extended to earlier stages of the disease as well. Once PD symptoms start to affect communication, the communication board might be used to train communicative skills and manual operation of electronic devices. The integration of exercise modules in the communication board might be particularly relevant for patients that suffer from earlier stages of PD. In this sense, one may think of the integration of salsa dance lessons, a proven method to slow down progression of the PD patient's symptoms, into the board. Integrating such dance lessons may even serve to improve the bond between ill and healthy partners. Since the communication board software is adaptable, the board might well be usable for PD patients in earlier phases of the disease. Further research could investigate the full extent to which the communication board designed in this study applies to other stages of PD.

In addition, PD is but one of many types of neurodegenerative diseases, such A.L.S. and Huntington's disease. What all these diseases have in common is that they entail the progressive loss of structure and function of brain neurons. In effect, this means that the brain and muscles lose their functional capacity. Because each neurodegenerative disease is different, and therefore brings with it its own set of communicative needs and patient limitations, this research focused on a single disease: Parkinson's Disease. However, due to the similarities between the different diseases, the findings from this research may well be applicable to other neurodegenerative diseases like A.L.S. and Huntington's disease. Further research could investigate the applicability of the communication board designed in this study to these other types of neurodegenerative diseases.

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Appendix 1 – Sample interview questions

- In what capacity are you connected / in touch with patients suffering from PD in your daily job?
- During my research I focus on the final phase of the disease; could you tell me what the issues in communication are for patients in this phase or patients that are almost in that phase? And how do these issues manifest themselves?
- Could you estimate the amount of patients that are unable to speak / communicate in the final phase of PD?

After further explanation of the research and the idea of a communication board the following questions were asked.

- Do you think patients could benefit from such a device? Could you explain in which kind of situations it could be useful? If you think it could not work or support the patient, could you explain why?
- Could you say how many patients are able to:
 - o Touch something / point to something?
 - o Press a physical button?
 - o Hit a button with some force?
 - o Draw something with their finger?
 - o Recognize photos?
- Do you have knowledge of research that supports these assertions?
- Do you have experience with existing assistive products that focus on communication? If so; could you indicate the strengths and weaknesses according to your experience?
- Do you have additional ideas for communication board hardware or software features?

Appendix 2 – Validation questions

Hardware [to be completed by researcher]:

- Screen size: *Is the patient able to touch all corners and sides? And can he see all corners and sides?*

Type of validation: Yes / No

- Manageability: *Does the communication board fit over a chair/wheelchair?*

Type of validation: Yes / No

- Stability: *Can the communication board support the weight of a 105 kg male on one side of the screen? And on the back of the screen?*

Type of validation: Yes / No

- Input: *Is the touch screen sensitive enough to respond to the touch of a PD patient?*

Type of validation: Yes / No

General software [to be completed with patient]:

- Speed web application: *Does the communication board show any signs of freezing or unwanted delays?*

Type of validation: Yes / No

- Navigation: *Does the patient understand how to navigate the board?*

Type of validation: Yes / No

- Intuitiveness: *Is the patient able to indicate pain? Is the patient able to indicate that he or she wants to go outside?*

Type of validation: Yes / No

- Forgiveness: *Is the patient able to continue using the board when he or she makes a mistake?*

Type of validation: Yes / No

- Friendliness: *Does the patient like using the board?*
Type of validation: Yes / No
- Visibility: *Can the patient see the icons on the screen? The text? The images?*
Type of validation: Yes / No
- Simplicity: *Does the board confuse the patient?*
Type of validation: Yes / No
- Speed: *Does the patient have time to process the information on the picture sliders?*
Type of validation: Yes / No

Improvement in communication [to be completed by caretaker]:

- *Which of the communication methods works best for the patient?*
 - Say it with icons
 - Say it with photos
 - I have pain
 - I feel ...
 - I want to say something**Type of validation:** Multiple choice, scale (1-5) for each section
- *Is the patient better able to communicate basic / necessary requests?*
 - Call for help
 - Use the toilet
 - Indicate hunger or thirst**Type of validation:** Scale (1-5) for each section
- *Is the patient better in 'extra' communication?*
 - Start a conversation?
 - Express emotions**Type of validation:** Scale (1-5) for each section

- *Are there other (positive or negative) changes in the patient's communication after using the prototype?*

Type of validation: Open question(s)

Back-end [to be completed by caretaker]:

- Intuitive: *How easy is it to:*
 - o Log in
 - o Add settings for the patient
 - o Upload pictures

Type of validation: Scale (1-5) for each question

- Usefulness: *Do you use the communication board with your patient? Why (not)?*

Type of validation: Open question(s)

- Usefulness: *Has the communication board improved your communication with the patient? Why (not)?*

Type of validation: Open question(s)

- Improvement: *How could the communication board be improved?*

Type of validation: Open question(s)