

Patiënten krijgen vaak vragenlijsten van fysiotherapeuten.



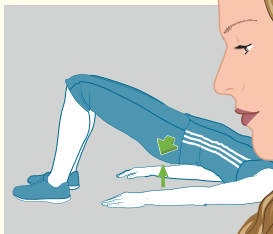
Veel patiënten hebben moeite met het invullen van vragenlijsten.



Onderzoekers, patiënten en fysiotherapeuten maakten samen een nieuw soort vragenlijst. Deze vragenlijst vult de patiënt in op een iPad. Het is daarbij niet nodig om te kunnen lezen of schrijven.



**De nieuwe vragenlijst is nog niet helemaal af,
maar patiënten zijn al heel erg tevreden.**



Toch gaan fysiotherapeuten de vragenlijst niet gebruiken.

Het maken van de vragenlijst kost erg veel tijd. Dit maakt de vragenlijst te duur.



Meer onderzoek is nodig. De eerste vraag hierbij is:

Zorgt de nieuwe vragenlijst voor goedkopere fysiotherapie van betere kwaliteit? Is dit zo? Dan kunnen zorgverzekeraars en de overheid misschien meebetalen aan het afmaken van de vragenlijst.

THE DUTCH TALKING TOUCH SCREEN QUESTIONNAIRE

Supporting patients with diverse levels
of health literacy in taking an active role
during the diagnostic phase
of physical therapy treatment

MARLIES WELBIE

THE DUTCH TALKING TOUCH SCREEN QUESTIONNAIRE

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Marlies Welbie

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ACADEMISCH PROEFSCHRIFT

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Promotor:

prof. dr. W.L.J.M. Devillé

Universiteit van Amsterdam

Copromotor:

dr. H. Wittink

Hogeschool Utrecht

Overige leden:

prof. dr. P.J. van der Wees

Radboud Universiteit Nijmegen

prof. dr. J.J.D.J.M. Rademakers

Maastricht University

prof. dr. R. Reis

Universiteit van Amsterdam

dr. M.P. Fransen

Universiteit van Amsterdam

dr. B.C. Schouten

Universiteit van Amsterdam

Faculteit der Maatschappij- en Gedragwetenschappen

Health is a social value and an individual right. It generates economic benefits for countries and is a prerequisite for national development and individual well-being.

Dr. Zsuzsanna Jakab,
WHO regional Director for Europe

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CHAPTER 1

General introduction



INTRODUCTION

The aim of the research project that is described within this thesis was to develop a tool which would help Dutch and Turkish physical therapy patients with inadequate health literacy (HL) to be more able to take an active part in the decision-making process within the diagnostic phase of physical therapy treatment in the Netherlands. Within this first chapter, the background and motivation for conducting this research project are described.

ACTIVE PATIENT PARTICIPATION INCREASES QUALITY OF CARE

Health care provision has evolved over the last decades. The traditional paternalistic approach, in which health care professionals were expected to make health care decisions for patients, is increasingly developing towards a patient-centered care (PCC) approach in which patients are expected to take on an active participating role [1]. Patient participation has been recognized worldwide as a means to enhance quality of care [2]. In contemporary health care systems, patient centeredness is placed alongside effectiveness and safety when it comes to measuring quality of care [1]. PCC is advocated in health care policies in many countries, including the Netherlands. Since 1995, the government has introduced a series of laws and regulations aimed at increasing autonomy and self-determination of patients [3]. Effective PCC has been proven to enhance patient experiences, reduce health care costs, and improve health [4]. Today, policymakers, institutions and health care professionals are striving for further development of shared decision-making and self-management in patients [5]. However, not all patients are able to take advantage of the positive effects of PCC, since PCC demands that patients participate as active partners [6] and information exchange is key to active patient participation [7].

LOW HEALTH LITERACY IS AN OBSTACLE FOR ACTIVE PATIENT PARTICIPATION

Inadequate health literacy (HL) is an important limiting factor in the ability of patients to take on an active role and exchange information with their health care provider effectively [8-10]. Within the Dutch population, thirty-six percent have inadequate health literacy [11].

HL is defined as the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain health [12]. Paasche-Orlow and Wolf created a conceptual model which describes the causal pathway between inadequate health literacy and health outcomes (see Figure 1.1) [13].

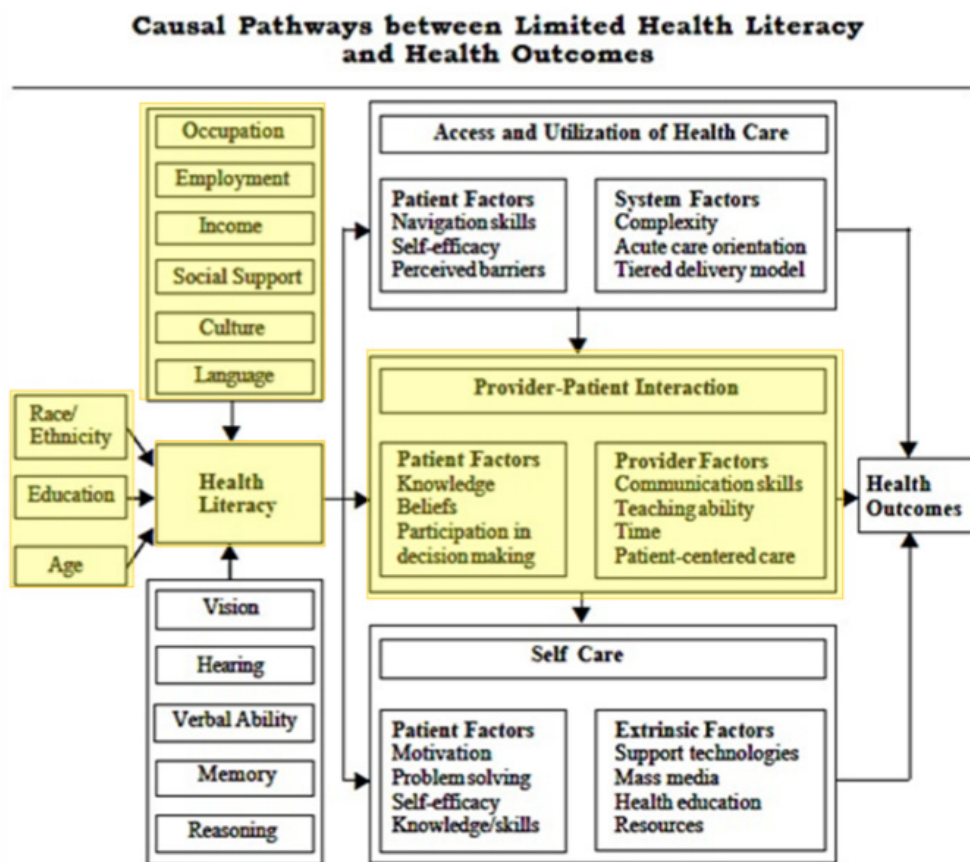


Figure 1.1 Conceptual model of causal pathways between limited health literacy and health outcomes [13]

According to the conceptual model of Paasche-Orlow and Wolf, inadequate health literacy causing problems within provider-patient interaction is one of the pathways through which health outcomes

are influenced negatively. Health literacy itself is, amongst other factors, influenced by ethnic background, socio-economic factors, language proficiency and age (see Fig. 1.1) [13]. While individuals with different social and ethnic backgrounds and levels of education do usually not differ in their desire for information, their approaches in seeking and offering information in interaction with their health care providers differ [14]. Ethnic minority patients and patients with less than high school education rate health care visits as less participatory [15,16]. Patients with low literacy tend to ask fewer questions during clinical encounters with their health care providers [17-19], though they do have concerns about being inadequately informed about their conditions and treatments [19]. Patients with low HL have trouble determining which information their health care providers need and which information might be irrelevant. They often lack the health care vocabulary to report symptoms accurately and may convey information illogically or in a jumbled order [20,21]. In addition, they often feel overwhelmed by information about their illness [18,21] and are more likely to be confused or underinformed about their own health conditions and the processes of care required to successfully manage these [20,22]. Having less knowledge about a disease influences the way patients interact with their providers. Patients with low HL are more likely to employ a passive communication style [17,18]. The tendency to be more passive complicates provider-patient interaction and leads to miscommunication [13,21], while more active patients receive better communication from health care providers [23]. Looking at the conceptual model of Paasche-Orlow and Wolf [13], finding a way to support patients with low HL to provide accurate and relevant information in a way that is comprehensible to their health care provider will improve provider-patient interaction, which will have a positive effect on their health outcomes.

QUESTIONNAIRES FACILITATE INPUT FROM THE PATIENTS' PERSPECTIVE

A provenly effective approach to improve provider-patient interaction and health outcomes is the use of Patient-Reported Outcome Measurements (PROMs). A Patient-Reported Outcome (PRO) is defined as any report of the status of a patient's health condition, behavior or experience with health care that comes directly from the patient without interpretation of the patient's response by a clinician

or anyone else [24]. In practice, a PROM is a standardized assessment using one or more questionnaires. Researchers and policy makers believe that routine PROMs have the potential to play a significant role in advancing the quality and patient-centeredness of health care [25,26]. Driven by positive research outcomes, they have been stimulating allied health professionals for decades, not in the least physical therapists, to implement PROMs into their daily practice [27]. Physical therapists use PROMs to guide diagnostic and treatment decisions, treatment planning and/or treatment evaluation. They help to evaluate the burden of disease and treatment from the patients' perspective [28], stimulate discussion of patient outcomes during consultations and facilitate provider-patient interaction [29,30]. Furthermore, they increase patient satisfaction about provider-patient interaction and clinically significantly reduce prevalence and severity of symptoms [31]. Using traditional paper-based questionnaires is not likely to contribute positively to the situation of patients with low HL though, because low HL is strongly associated with low literacy [32]. Therefore one can assume that in patient populations with low HL the use of questionnaires will not contribute to provider-patient interaction but in fact might complicate the situation further. However, previous research has shown that the use of a Talking Touchscreen (TT) increases the ability of patients with low literacy to complete health-related questionnaires, even if they have limited or no computer skills [33-44].

ADDING TECHNOLOGY INCREASES THE ABILITY OF PATIENTS WITH LOW HEALTH LITERACY TO COMPLETE QUESTIONNAIRES

In 2003, Elisabeth Hahn and David Cella were the first authors to describe the necessity of developing a Talking Touchscreen (TT) for patients with low literacy [33]. Within this key paper, they drew a very detailed picture of the disadvantaged position of this vulnerable population when it comes to health and the ability to make effective use of health care. This description fits perfectly with the causal pathways whereby inadequate HL leads to low health outcomes, which were later on described by Paasche-Orlow and Wolf (see Fig. 1.1) [13]. The disadvantaged position of low literacy people in a health care context described by Hahn et al. in 2003 [33] still applies to low literacy people in the Netherlands today [45-47]. Research shows that adding TT technology to questionnaires increases the usability of PROMs for

low (health) literacy patients [33-44]. This opens the possibility for this disadvantaged group to take advantage of the positive effects that using PROMs has on provider-patient interaction [25,26,28-31]. According to the conceptual model of Paasche-Orlow and Wolf, this should eventually influence health outcomes positively [13].

MINORITY GROUPS ARE EVEN MORE VULNERABLE WHEN IT COMES TO HEALTH LITERACY AND COMPLETING QUESTIONNAIRES

Specific subgroups of patients with low HL are formed by patients with low literacy who do not master the native language of the countries in which they live and who belong to a minority group. A 'minority group' was defined by Tourangeau et al. as *"a group of residents in a nation state, which is a distinct subgroup of that state's resident population. It is in a non-dominant position, endowed with cultural or linguistic characteristics that differ from other groups. The subgroup has an internal cohesion based on its distinct characteristics."* [48]. People with a Turkish background form the biggest minority group in the Netherlands with 400,367 people [49]. In 2016, The Netherlands Institute for Social Research reported the following characteristics of this minority group: approximately one-third of the Turkish people between 15 and 65 years of age in the Netherlands only went to primary school in comparison to six percent of the Dutch population. Younger people and people who are born in the Netherlands to Turkish parents identify strongly with Turkish people and spent most of their free time with people who identify themselves as Turkish too. Fifty-seven percent of parents with a Turkish background never or almost never communicate in Dutch with their children [50]. The number of people with low literacy and low HL within this population is unknown but, since education and literacy are very strongly associated [51,52] and language, ethnicity, culture and educational level are factors that influence health literacy [13], one can assume that low literacy and low health literacy are overrepresented within this group. In order to reduce health inequality between native and minority groups, researchers of earlier publications on TTs emphasized the importance of creating different language versions of TTs in order to accommodate minority populations [33,34,37,38,41,42].

OBJECTIVES AND OUTLINE OF THIS THESIS

Application of TT technology within Dutch health care was not described in the literature prior to this PhD project, even though the technology to build it existed. The aim of the current research project was to adapt the most frequently used questionnaire in Dutch physical therapy practice and add TT technology to it in a way that would support Dutch and Turkish physical therapy patients to explicate symptoms, limitations and treatment goals during the diagnostic phase of their physical therapy treatment process. Because it is not ethical nor practical to differentiate levels of HL of patients in clinical practice by starting the treatment process with a time-consuming and burdening health literacy assessment, the researchers of the current project wanted patients of all HL levels to be capable and feel comfortable using the questionnaire.

For the research project that is described within this thesis, the Patient-Specific Complaint Questionnaire (PSC) [53,54] was taken as a starting point for the development of a Dutch version of the TT, called the Dutch Talking Touch Screen Questionnaire (Dutch TTSQ) [55]. The PSC was chosen because it was the most frequently used questionnaire in Dutch physical therapy practice [55,56]. Its content fits the goal of helping patients to provide relevant information regarding their health problem to their physical therapist. It aims to make the patient select his or her main limitations in functioning and formulate his or her own specific treatment goals. This paper-based questionnaire is responsive and sensitive to change in complaints that are highly relevant to the individual patient [53,54,55].

The first objective within the current research project was to assess which problems physical therapy patients with diverse levels of HL, and Dutch and Turkish backgrounds, encountered during completion of the PSC [53,54]. The results of this study which are described in **Chapter 2**, led to the second objective of the research project, which was the development of a working prototype of the Dutch TTSQ, described in **Chapter 3**. Based on the lessons learned during this process, guidelines for designing interactive questionnaires for low literacy persons were given within this chapter. The last objective was to test whether the newly-developed Dutch TTSQ generated accurate information on symptoms, limitations and treatment goals of patients with diverse

levels of HL in a physical therapy context and to test and compare the usability of the Dutch TTSQ and its Turkish translation. In **Chapter 4.1**, the accurateness of the information gathered through the Dutch version of the TTSQ in a population of physical therapy patients with different levels of HL and a Dutch background are evaluated. **Chapter 4.2** evaluates the usability of the Dutch version of the TTSQ in a population of physical therapy patients with different levels of health literacy and a Dutch background. **Chapter 4.3** describes the evaluation of the usability of the Turkish version of the TTSQ in a population of physical therapy patients with different levels of HL and a Turkish background living in the Netherlands.

In **Chapter 5** the results of the different studies presented in this thesis are summarized and put into a broader perspective. Additionally, recommendations for further research and development of talking touchscreens for use in clinical practice to support patients with low HL to participate more actively in provider-patient interaction are given.

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CHAPTER 2

Perceived ease of use and usefulness of the Dutch
Patient Specific Complaints Questionnaire
by patients with Dutch and Turkish backgrounds
and diverse levels of literacy



Completing the Patient Specific-Complaint Questionnaire
in physical therapy practice is problematic for high and low
literate patients: a qualitative study

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ABSTRACT

Objective to get insight into the perspectives of physical therapy patients with different levels of health literacy on 'ease of use' and 'usefulness' of the most frequently used questionnaire in Dutch physical therapy: the Patient Specific-Complaint questionnaire (PSC).

Methods Cognitive interviews were conducted with twenty-five Dutch and twenty-five Turkish physical therapy patients with variable health literacy levels after they completed the Dutch PSC. A thematic content analysis approach was used to analyze the data.

Results Nineteen respondents did not complete the PSC fully and ten were not able to complete the questionnaire at all. All respondents but one experienced difficulties completing the PSC. Most problems were experienced in understanding and interpreting the instructions and questions. Low educated and low health literate respondents experienced more difficulties than high educated and adequate health literate respondents did. Due to these difficulties in twenty-four cases the PSC generated other information than was intended by its developers. Almost half of the respondents were positive about the usefulness of the PSC in relation to their treatment process.

Conclusions Completing questionnaires is more difficult for patients than care providers might realize. The results of this study confirm the necessity to collaborate with patients in all stages of questionnaire development. The ease of use of questionnaires should be tested and if necessary improved. To stimulate questionnaire developers to take usability and face and content validity into account, it is recommended to incorporate assessment of these criteria in quality evaluation tools like the COSMIN checklist.

INTRODUCTION

Researchers and policy makers believe that routine Patient-Reported Outcome Measurements (PROMs) have the potential to play a significant role in advancing the quality and patient-centeredness of health care [1,2]. A Patient-Reported Outcome (PRO) is defined as any report of the status of a patient's health condition, behavior or experience with health care that comes directly from the patient without interpretation of the patient's response by a clinician or anyone else [3]. Driven by positive research outcomes, policy makers have spent well over two decades increasingly stimulating allied health professionals, not in the least physical therapists, to implement PROMs into their daily practice [4,5]. Physical therapists use PROMs to guide diagnostic and treatment decisions, treatment planning and/or treatment evaluation. It helps to evaluate the burden of disease and treatment from the patients' perspective [6], stimulates discussion of patient outcomes during consultations, increases patient satisfaction about patient-provider-interaction and clinically significantly reduces prevalence and severity of symptoms [7]. Researchers and policy makers use PROMs at an aggregate level for comparative effectiveness research [8], assessment of the performance of clinicians and organizations, public reporting and value based payments [9]. They stimulate routine application of PROMs by clinicians, believing aligning clinical practice and performance measurement will maximize the impact of PROMs on the quality of health care [2].

Implementation of integrated use and routine application of PROMs into physical therapy practice has proven to be a complex and challenging process [2]. Physical therapists are more skeptical about using PROMs in the clinical setting than researchers and policy makers are and they experience significant barriers in routine application [5, 10,11]. Experts from the United States, England and The Netherlands state that having patients advocate the integrated use of PROMs would be an important facilitator. They add that for patients to become advocates, they must recognize this way of data collection as useful to their health and health care [2]. This approach is questionable, for little is known about the way patients perceive the usefulness of PROMs. Results from studies conducted in the mental health sector indicate that perceived usefulness from the patient perspective varies from partly positive [12] to completely negative [13].

In this present study a revision of the definition of Davis [14] is applied to define 'perceived usefulness': 'the degree to which a person believes that using a questionnaire would enhance his health care process'.

Not only is perceived usefulness of PROM important for patients to become advocates, they should also perceive questionnaires as 'easy to use' [10]. A revision of the definition of 'perceived ease of use' of Davis is used in this study [14]: 'the degree to which a person believes that using a particular questionnaire would be free from effort'. Large groups, in particular people with low literacy, lack the necessary skills to complete questionnaires. In the Netherlands this concerns 11% of the adult population. Of this 11%, two-thirds has a Dutch and one third a non-Dutch ethnic background [15]. In addition to being low literate, this group generally also suffers from low numeracy and limited problem solving skills [16].

Literacy, numeracy and problem solving skills are all relevant for completing questionnaires. Patients with low literacy are therefore vulnerable when it comes to the usefulness and 'ease of use' of questionnaires [17]. Questionnaires are normally text-oriented and presented in a concentrated format which is hard to grasp for low literate persons. It can be questioned whether using questionnaires in a low health literate patient population contributes to their quality of care. It may even complicate the situation. Possible mistakes made by the patient in completing the questionnaire may lead to invalid information. Insufficient literacy, numeracy and problem solving skills might lead to problems in the response process which according to Tourangeau and colleagues exists of four phases: 1. understanding and interpretation of the questions, 2. retrieval of the necessary information from memory, 3. making a judgment about the information needed to answer the question, and 4. responding to the question by choosing the most fit answer possibility [18]. Problems in the response process might yield different information than was intended by its developers. Moreover, the burden of having to complete a task which is hard to fulfil can lead to emotional strain, which makes it even harder for a patient to cope with the complex context of a health care setting.

Low literacy is strongly associated with low health literacy [19]. The World Health Organization defines health literacy as the cognitive and social skills which determine the motivation and ability of individuals

to gain access to, understand and use information in ways which promote and maintain good health [20]. Reading ability, language, level of education and ethnic background are all determinants of health literacy [17,21].

Results of studies that explored 'perceived ease of use' show that patients perceive the ease of use of questionnaires as too low [22-25] up to acceptable [26]. In none of these studies nor in the earlier mentioned studies on perceived usefulness the level of education or (health) literacy of the respondents was taken into account. This makes it difficult to generalize these results to actual patient populations as low educated / (health) literate people are generally overrepresented in patient populations yet underrepresented in research populations [27].

The objective of this study was to get insight into the perceived ease of use and perceived usefulness of a PROM by patients with various levels of health literacy in the Dutch physical therapy context. For this purpose, patients with diverse levels of health literacy, levels of self-proclaimed reading ability, native languages, ethnic backgrounds and educational levels were invited to participate. In the context of this study patients with Dutch and Turkish backgrounds were approached. This last group was chosen because they form the largest group of immigrants in The Netherlands [28]. As for the questionnaire, the Dutch Patient-Specific Complaints questionnaire (PSC) [29] was selected. The PSC is the most frequently used PROM in Dutch physical therapy [11] and several Dutch health care insurance companies and the Royal Dutch Society for Physical Therapy stimulate its use in physical therapy practice [5]. The PSC is responsive. It is sensitive to change on complaints that are highly relevant to the individual patient [29,30]. The content of the Dutch PSC is very similar to the internationally better known Patient-Specific Functional Scale [31].

Objectives

The aim of this study was to get a first impression of the perceived ease of use and perceived usefulness of PROM by patients with diverse levels of health literacy in the Dutch physical therapy setting. This aim led to the following research questions:

1. How do Dutch and Turkish physical therapy patients with diverse levels of health literacy perceive the ease of use of the PSC?
 - a. What problems arise within the response processes of Dutch and Turkish physical therapy patients with diverse levels of health literacy who complete the PSC?
 - b. Does the information that is generated by the PSC in a Dutch and Turkish physical therapy patient population correspond to the information that the developers of the PSC intended it to generate?
2. How do Dutch and Turkish physical therapy patients with different levels of health literacy perceive the usefulness of the PSC?

METHODS

Design

A qualitative study of fifty cognitive interviews [32] was conducted using the probing method as described by Collins [33].

Sampling and procedure

Recruitment took place in eight physical therapy private practices in deprived areas of Utrecht, The Netherlands and was aimed at including respondents of all levels of education, self-proclaimed Dutch reading and writing skills and health literacy. Health literacy was measured with the Dutch version of Chew's Set of Brief Screening Questions (SBSQ-D) [34]. In order to increase detection of cultural or lingual barriers an equal number of Dutch and Turkish respondents was recruited. Every newly referred Dutch or Turkish patient who was unfamiliar with the PSC was invited by their physical therapist to participate in this study. To decrease the chance of unintentional exclusion of low (health) literate patients the recruiting therapists were trained to recognize signs of low literacy and optimize their

ability to inform patients in plain language. Furthermore, recruitment information was provided in plain written Dutch and Turkish language. The information material included a compact disc on which the written information was recorded in spoken language, so patients would be able to hear the information as well as read it. During the course of the study one hundred and forty eligible patients were invited. Forty-two Turkish and forty-eight Dutch patients were unwilling to participate due to different reasons such as lack of interest, energy and time and 'feeling too ill'. Informed consent was obtained from all individual participants included in this study using a plain language consent form and verbal explanation.

Data collection

In accordance with respondents' preferences interviews took place at respondents' homes or at the physical therapy practice. Interviews were audio taped unless the respondent did not permit that, which occurred in six cases. In these cases the researcher took notes. In case of a language barrier the help of a professional interpreter was called in by telephone. In four cases respondents refused working with a professional interpreter. One of these four respondents asked her husband to act as an interpreter. For each interview the same procedure was followed:

Observed by researcher MW, who conducted all interviews, respondents completed the PSC without receiving any help or instruction. The aim of the PSC is described by its developers as follows: The PSC is focused on activities that an individual patient selects as main complaints. It is essential that patients select activities that their physical condition made difficult for them, that are important for daily living, and that are difficult to avoid [29]. The PSC contains four sections. The first section comprises a list of suggestions of physical activities in which one can be limited. Patients are allowed to select from or add activities to this list that apply to their situation. In section two a maximum of five activities of section one are selected. These should be the activities which the patient wishes to improve first. In section three the three most important activities of section two are selected and prioritized. In section four, the current difficulty to carry out these three activities is rated on an eleven point Numeric Rating Scale (0 – 10; 0 stands for no effort at all and 10 for every effort imaginable). During observation of completion of the PSC the researcher took

notes on the practical approach and nonverbal and verbal reactions of the respondent. Afterwards the respondents' experience of the ease of use of the PSC was thoroughly discussed during an interview. The topic list of the interview contained: reading and comprehension level of the PSC, reasons for unanswered questions of the PSC and possible experienced emotional strain. To get more insight into the response process and the type of information that was generated by the questionnaire respondents were asked to formulate the PSC questions in their own words and describe how they went about answering them [32]. In relation to the perceived usefulness of the PSC respondents were asked to articulate to what degree they believed that using the PSC would enhance their health care process and why they believed this. Furthermore, they were asked if they would appreciate it if their physical therapist would ask them to complete the PSC; and how they would value their physical therapist and treatment process if the PSC would be used.

Data analysis

After the audiotaped interviews were transcribed verbatim the data were analyzed using a thematic content analysis approach [35]. Researcher MW started with open coding, coding all fragments of all transcripts. To get more familiar with the data and to create an overview the researcher made a descriptive summary of each case after she finished open coding. Each summary contained all emerging themes regarding perceived ease of use of the PSC, the response process, the type of information that was generated through the PSC and perceived usefulness of the PSC. The emerged themes in the summaries were supplemented with related field notes, respondents' demographics, self-proclaimed Dutch reading and writing skills, health literacy level and if applicable missing data and/or refusal of completing the PSC.

Then the researcher took an interpretative and inductive approach regarding perceived ease of use and perceived usefulness by listing emerging 'themes' from the descriptive summaries.

A more deductive approach was taken in order to identify problems that arose within the response process and information that was generated by completing the PSC which did not correspond to the intention of the PSC developers. Themes related to the response

process and generated information were structured according to the four stages of the response process as described by Tourangeau [18]. Problems within the response process and information not corresponding to the purpose of the PSC were identified, labeled and added to the earlier mentioned coding scheme as part of the concept of 'perceived ease of use'.

As a last step researcher MW compared the analyzed interviews of Dutch and Turkish respondents as well as low, moderately and highly educated respondents, respondents with adequate and low health literacy and respondents who were and were not able to complete the PSC independently. By comparing the codes within and between the groups she looked for possible different patterns in relation to perceived ease of use, problems in the response process, generated information and perceived usefulness. Again this step was repeatedly checked by and discussed with researchers HW and MJW.

Background of the researchers involved in the analysis process

Marlies Welbie (MW) MSc is a health scientist and physical therapist by training. She worked in a private practice in a deprived area in Amsterdam, The Netherlands for five years prior to this study. She had no prior relation to the respondents. Harriet Wittink (HW) PhD is a researcher and physical therapist by training. She has extensive experience in the use of PROMs in clinical practice in patients with various ethnic backgrounds and literacy levels in an urban hospital setting. Marjan J Westerman (MJW) PhD is a philosopher and physical therapist by training. She has extensive experience in qualitative research methods and especially in response behavior in the measurement of self-reported outcomes.

RESULTS

PSC ease of use

Table 2.1 shows that twenty-one respondents completed the PSC, nineteen respondents did not fill out one or more items and ten respondents did not answer any item.

Table 2.1 Background of respondents subdivided according to their ability to complete the PSC

	Correctly completed	Partly completed	Not completed			
Amount and background respondents	Dutch n=15	Turkish n=6	Dutch n=9	Turkish n=10	Dutch n=1	Turkish n=9
Mean age (range)	67,4 (47-83)	35,67 (24-47)	66,44 (46-82)	40,5 (25-56)	79	62,6 (48-79)
Gender: m/f	7/8	1/5	4/5	4/6	0/1	6/3
Educational level low/moderate/high*	0/8/7	2/3/1	0/4/5	3/6/1	1/0/0	9/0/0
Health literacy inadequate/adequate**	0/15	1/5	0/9	7/3	1/0	9/0
Self-proclaimed Dutch writing skills						
Good	15	4	8	4	0	0
Sufficient	0	2	1	1	0	0
Insufficient	0	0	0	5	0	3
None	0	0	0	0	1	6
Self-proclaimed Dutch writing skills						
Good	14	3	7	2	0	0
Sufficient	1	3	2	3	0	0
Insufficient	0	0	0	3	0	0
None	0	0	0	2	1	9

* low = maximum primary school completed

moderate = everything between primary school and bachelor degree

high = minimum bachelor degree

**according to the SBSQ-D

All respondents, except for one highly educated, adequate health literate 47 year old Turkish male team manager who fully completed the PSC, experienced difficulties reading and comprehending the PSC. Most comprehension problems were experienced with the introduction and instruction of the questionnaire. The respondents thought the text was too long and contained antinomies.

Example:

- Try to recognize the activities that gave you trouble in the last week due to your limitations. We ask you to select the activities which are very important to you and you would mostly want to see improve in the next few weeks -.

A male Dutch highly educated adequate health literate 46 year old lawyer who fully completed the PSC reported:

"It is very chaotic and confusing. First it says try to recognize the activities with which you had difficulties in the last week. And then it says try to recognize the most important activities that you would like to improve in the next few weeks. That is quite contradictory. In addition, it does not say to which sections the instruction is related. So I am wondering and constantly reading back thinking 'What do I have to do with this section exactly? Is it related to the first or the second question?' I can imagine I would refuse completing this questionnaire thinking it is of no use and I should be handed a properly designed questionnaire."

A similar remark was made by a 37 year old low educated adequate health literate Turkish female volunteer in the welfare sector who fully completed the PSC but provided other information than was intended by its developers:

"When I finally got it it was not so hard. But I had to read it twice and very careful before I really understood what was meant. What they mean is 'what is it that you need help for'. That could be said much easier; in plain language. These sentences are much too long and complicated. Especially when you have trouble with the Dutch language."

Based on the introduction not all respondents understood that the selected activities should be part of their physical therapy goals. An 81 year old female Dutch moderately educated adequate health literate retired obstetrical nurse who fully completed the PSC:

"Look, walking is problematic because of my legs. I have what they

call polyneuropathy. Walking is not what it used to be. I have to watch carefully where I place my feet. So walking on an uneven surface is difficult for me. That is why I selected this activity."

Interviewer: '

"Do you want your physical therapist to help you with that?"

Respondent:

"No. I go to my physical therapist because lately I got this problem in my shoulder and that causes pain in my arms sometimes. For instance when I lie in bed or when I get dressed." Interviewer: "Why haven't you selected these activities?"

Respondent:

"I did not interpret the question that way."

A 51 year old low educated low health literate Turkish female housekeeper who partly completed the PSC:

"I selected running, biking, grocery shopping, driving a car and I added handicrafts and helping people. I like running and it is healthy too, so that is very important to me. Shopping for groceries relaxes me. These are all pleasant things that make me feel good. That is why they are so important to me."

Interviewer:

"And is it hard for you to do these things at this moment because of physical impairments?"

Respondent:

"No not at all! These are just the things that are very important to me."

Suggested activities in section one of the questionnaire were interpreted differently by different respondents. A Dutch adequate health literate 74 year old retired professor of chemistry who completed the PSC stated about the suggested activity 'walking, taking a walk':

"When it says 'walking, taking a walk' I don't know what it means. Do they mean moving around, walking fast, hiking? Those are very different activities."

Some respondents interpreted the term 'physical activity' in itself different from what the developers of the PSC intended. A 63 year old Dutch highly educated adequate health literate teacher who partly completed the PSC:

"When I think of physical activities I think of biking, doing sports and those kinds of things. I do not think of 'turning over in bed'."

When being asked to list the three most important physical activities for which he wanted physical therapy, this respondent did not write

down 'turning over in bed' even though this was his first treatment goal:

"Because I do not associate 'turning over in bed' with physical activities, I did not think of writing that down in this section even though it was mentioned as an activity in section one of this questionnaire".

Twenty-seven respondents had trouble with finding a well-fitting answer possibility. A Dutch highly educated adequate health literate 76 year old male retired teacher who partly completed the PSC had an unpleasant feeling in his legs, but it did not cause physical activity limitations. Even though he never ran and did not want to run anymore, he selected walking and running because he felt he had to give an answer and those two items were the most logical in relation to his condition. A 62 year old highly educated adequate health literate Dutch female management assistant who partly completed the PSC had some limitations but stated:

"When I go to the doctor I tell my doctor my arm hurts. I do not tell my doctor in what kind of activities I am limited because of the pain. I do not think a patient thinks like that. I myself have never described my condition like 'I cannot make the beds anymore'."

Two Dutch and thirteen Turkish respondents reported they had trouble reading the Dutch language. A 51 year old low educated, low health literate Turkish female housekeeper who partly completed the PSC:

"It is hard for me. I understand most words separately. But I do not always understand the overall meaning or message of a sentence or paragraph. And then I do not really understand what is being asked of me."

Two Turkish females, 25 and 39 years of age who had completed the PSC fully and correctly stated they experienced some difficulties comprehending small parts of the PSC. The twenty five year old moderately educated adequate health literate female cashier said:

"I am not sure what 'walking on a level surface' means. I think it means 'just walking around'."

Having trouble reading causes feelings of insecurity and makes completing questionnaires harder, annoying, more time-consuming and tiring. A 24 year old low educated low health literate unemployed Turkish female who fully completed the PSC said:

"I do not want to complete questionnaires in Dutch. It is so much work for me, it's very tiring. I have trouble understanding everything, you know. That makes it very hard for me."

A Dutch 79 year old uneducated, low health literate female housewife who did not complete the PSC at all was very ashamed of her illiteracy and hid it from everybody outside of her close family and friends. She described that being presented a questionnaire by a physical therapist would be stressful and upsetting to her. She spent a lot of energy masking her illiteracy and worrying about being exposed.

Due to errors in the response process, in twenty-four cases, the PSC generated different information than was intended by its developers. Instead of selecting activities in which respondents were limited they, for instance, selected activities they were able to do or which were important to them, gave them the most joy or which most frequently occurred. A 51 year old low educated low health literate female Turkish volunteer at the mosque who partly completed the PSC explained what she wrote down as her first of five priorities:

"I wrote down: 'Being a bridge between people of different cultures', because that is my main goal in life. That's what drives me. I would love for people to better accept and understand each other. I want to contribute to that."

Comparing the amount of reported problems related to 'ease of use' of the PSC and the nature of these reported problems between different subgroups the following patterns were identified: higher educated and adequate health literate respondents were better able to complete the PSC than lower educated and low health literate respondents. This is also reflected in table 2.1. Lower educated, low health literate and Turkish respondents more often had problems with reading and understanding words and phrases than higher educated, adequate health literate and Dutch respondents. Higher educated, adequate health literate and Dutch respondents more often had problems with interpreting the meaning of the questions and answers given in the questionnaire. Problems in the response process more often led to generation of different information than was intended by the developers of the PSC if respondents were low or moderately educated and low health literate.

PSC usefulness

Forty-four respondents spoke about the usefulness of the PSC in relation to their health care process. Six respondents of diverse health literacy levels and ethnic background stated they did not have

an opinion on this topic. Twenty-three of them were not positive. If asked, they would complete the questionnaire purely as a favor to their therapist. A Dutch 62 year old highly educated, adequate health literate female management assistant:

"Well, I will complete this questionnaire if my therapist asks me to. I am dependent on her."

These respondents did not feel helped by completing the PSC and preferred to speak with their therapist. They stated that personal contact is more effective and enables them to give more accurate and detailed information in less time with less effort. They wanted 'to feel seen' by their physical therapist. A highly educated, adequate health literate 47 year old Turkish male team manager:

"It is very important that you get the feeling that the therapist has enough time and attention for you. Otherwise you don't feel taken seriously. At the end of the day you just want to get rid of your pain; you just want the therapist to help you and to thoroughly analyze your situation. Maybe a therapist can analyze my situation on the basis of a questionnaire, but that is not what I expect a therapist to do. I want the physical therapist to look and feel and really give me his full attention."

Twenty-one respondents were positive about the usefulness of the PSC in relation to their health care process. It made them feel more involved in their treatment and could help them and their therapist to prepare for the first consultation. A Dutch 49 year old moderately educated, adequate health literate male ICT specialist:

"Not everybody is equally aware of themselves, of what their specific problems are. When you are at the therapist all over sudden you have to think about what your problems are, what caused them exactly and where and when you feel it. I am not always properly prepared for that. This questionnaire helps you to think about it in advance. Maybe it sounds strange, but in general I just want to be happy and I don't want to know that I have problems."

A majority of the Turkish respondents added that use of the PSC would help in diminishing language barriers if it were translated into the Turkish language. A Turkish 24 year old low educated low health literate unemployed female:

"Because of my poor Dutch I can only describe my condition in very short sentences like 'painful legs' or 'burning feeling'. But it is hard for me to explain myself further. Like what effect this has on my life, for instance. A Turkish version of the questionnaire would help me to

give more information to my therapist."

No salient differences were seen in the level of education, ethnic background, Dutch reading and writing and health literacy skills and ability and inability to complete the PSC between the groups of people that did and did not think of the PSC as useful in relation to the quality of their health care process.

Six respondents, all of Dutch origin, spoke about the usefulness of the PSC outcomes on an aggregate level. None of them were positive. They feared violation of their privacy and they distrusted health insurance companies. A 61 year old moderately educated, adequate health literate bus driver instructor said:

"If a therapist asks me to complete a questionnaire, I would think he is not serving his patients, but the health insurer. Because the reality is, that if a therapist does not obey the health insurers he will lose his job. The health insurer is very dangerous. Not everybody realizes that. What troubles me in terms of my own situation is that if I complete this form and on the basis of my answers my health insurer thinks that I am very ill and expects me to have to go to the doctor very often in the future, they might raise the price of my health insurance or throw me out of their insurance."

DISCUSSION

The aim of this study was to get insight into the perceived ease of use and perceived usefulness of the PSC by physical therapy patients with different levels of health literacy. Overall, the respondents were not positive about the ease of use of the PSC. All respondents, except for one, experienced problems completing the questionnaire. Most problems were related to the understanding and interpretation of the instructions and questions. Due to these problems the PSC generated different information than was intended by its developers in twenty-four cases. Low health literate respondents experienced more problems during their response process than adequate health literate respondents did and this more often led to generation of different information than was intended by the developers of the PSC. This may be related to the fact that high health literate persons have better problem solving skills than low health literate persons have [16]. Ten respondents, all low health literates, were not able to complete the

questionnaire at all. Almost half of the respondents were not positive about the usefulness of the PSC in relation to their health care process. Six respondents spoke about using PSC outcomes at an aggregate level. They were all worried about their privacy and feared that this could turn against them if they would need more or more expensive treatment than the 'average patient'.

The developers of the PSC reported issues about the ease of use of the PSC in one of their first publications on the questionnaire in 1999 [29]. They wrote that during the first intake patients were often surprised and needed time to think about the selection of activities. They advised to use two intake visits to give patients time to reflect on activities that were limited due to their health problem between these two intakes. They added that they realized that planning two intake visits would probably not always be practical. They suggested that it might be possible to have only one intake visit if prior to the intake patients would be asked by telephone or email to pay attention to activities of daily living that are limited due to their health problem [29]. This complex assignment might be hard to understand for low health literate patients, especially when it is given over the phone or by email. Furthermore the developers of the PSC stated that for the selection procedure within the PSC an interviewer is needed to insure that patients select activities that their health problem made difficult for them, that are important to them, and they find difficult to avoid. But they also hypothesized that it could be possible to replace the interviewer by a better formulated instruction [29]. Based on the results of this study it can be concluded that with the current written instruction the majority of our respondents would have needed help from an interviewer to be able to complete the PSC as the developers intended. From prior experience as clinicians and from feedback from the participating physical therapists in this study, the researchers of the current study know that physical therapists often take on the suggested role of interviewer when they use the PSC in their practice. They help patients completing the questionnaire by reading the questions out loud and explaining the meaning of the questions and answers if necessary. This is very time consuming and therefore takes up valuable treatment time. Helping the patient might also diminish the validity of the results of the questionnaire while it is hard to determine to what extent the response process is influenced by the person who is helping the patient. This also applies to family or friends

assisting a patient to complete a questionnaire in case of language barriers or low literacy. Standardizing the role of the interviewer is another problem. If the role of the interviewer is not standardized, and there are no indications that it currently is, reproducibility and inter- and intra-reliability of the PSC is questionable. Instead of using a 'real life' interviewer, existing ICT technology could help to make the PSC easier to use. If the PSC were to be digitalized the role of the interviewer could be taken over by computer assistance. This would solve the problem of standardizing the given assistance. Furthermore, through speech technology patients could be enabled to hear as well as read the questions and by adding touchscreen technology patients could be enabled to give answers without the necessity of using a keyboard or computer mouse or having to write down the answers. Previous studies have shown that adding such technology successfully increases the usability of health related questionnaires for low literate patients [37-43]. Looking at the results of the current study the PSC should also be translated into the native languages of, at least, the largest immigrant groups of the Netherlands.

Making the PSC easy to use, especially for low health literate patients, could potentially help enhance the quality of care of this vulnerable population. The purpose of the PSC is to help patients to formulate their three most important physical therapy treatment goals. People with limited health literacy have little knowledge about their own health conditions, which has broad ramifications on how they interact with their health care providers. Patients with low health literacy skills have trouble determining which information their providers need and which information is irrelevant. They often lack the health care vocabulary to report symptoms accurately and may convey information illogically or in a jumbled order [44]. Using the PSC could therefore play a potentially important role in increasing the quality of the patient-provider-interaction between physical therapists and low health literate patients. Perceived ease of use has a positive influence on perceived usefulness [14]. Making the PSC easier to use might therefore at the same time increase patients' perceived usefulness of the questionnaire.

The findings on perceived ease of use of the PCS in our study are in accordance with the findings of four other studies on ease of use of specific questionnaires [22-25]: all four studies except for the study of

Liu et al. [23] reported that their respondents had problems reading and comprehending the questionnaires. All studies found difficulties with the interpretation of questions and response categories due to different perspectives between patients and the developers of the questionnaires. This gives rise to test and if necessary adjust the comprehension and readability of questionnaires on a wider scale.

The results of this study confirm the necessity to collaborate with a target population in all stages of questionnaire development. This not only ensures that the questionnaire comprises concepts and language that is relevant to patients but it also strengthens its face and content validity [45]. Developers should strive to engage representatives of the full variety of patients of their target population in the development process. This means they should use recruitment strategies and research designs that consider the needs of low as well as adequate (health) literate patients. To stimulate questionnaire developers to take ease of use, face and content validity of PROM into account, it is recommended to incorporate assessment of these psychometric criteria in quality evaluation tools like the COSMIN checklist [46].

Strengths and limitations

A limitation of this study is that the PSC was completed in the context of this research, not as part of the physical therapy treatment of the respondents. This seems to have caused some respondents to lose sight of the fact that they should have linked their response selection process to their physical therapy goals. Furthermore the refusal of four of the respondents to work with a professional interpreter caused language problems, which led to less depth in their interviews.

A strength of this study is the large variety of levels of education and literacy within the research population. This contributes to the validity of this study. The fact that only two Dutch respondents seemed to have insufficient Dutch reading skills does not diminish that. These two respondents are exemplary in the way they speak about and handle their inabilities. Because of the taboo on low literacy among Dutch natives it is very hard to include these respondents in research projects [36].

Practice implications

Patients have more difficulty than we may realize with understanding and completing questionnaires. When using questionnaires, patients should be explained what the purpose of the questionnaire is and the results should be discussed with the patient by clearly relating them to the diagnosis, prognosis, proposed treatment goals and/or evaluation of treatment effects. In addition, we need to think about ways that make questionnaires more accessible to patients in clinical practice, such as easier wording, speech and touchscreen technology and/or more visual presentation of questions. Patients are a long way off from becoming advocates for PROMs use in clinical practice.

Acknowledgements and Disclosures

All procedures performed in this study were in accordance with the ethical standards of the Medical Ethics Committee of the Academic Medical Centre of Amsterdam and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The authors do not report any conflicts of interest.

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CHAPTER 3

Development of the Dutch Talking Touch Screen Questionnaire



Deriving guidelines for designing interactive questionnaires
for low literate persons; development of a health assessment
questionnaire

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ABSTRACT

Large groups in society, in particular people with low literacy, lack the necessary proactivity and problem-solving skills to be self-reliant. One omnipresent problem area where these skills are relevant regards filling in forms and questionnaires. These problems could be potentially alleviated by taking advantage of the possibilities of information and communication technology (ICT), for example by offering alternatives to text, interactive self-explaining scales and easily accessible background information on the questionnaires' rationale. The goal of this paper is to present explorative design guidelines for developing interactive questionnaires for low literate persons. The guidelines have been derived during a user-centered design process of the Dutch Talking Touch Screen Questionnaire (DTTSQ), an interactive health assessment questionnaire used in physical therapy. The DTTSQ was developed to support patients with low health literacy, meaning they have problems seeking, understanding and using health information. A decent number of guidelines have been derived and presented according to an existing, comprehensive model. Also, lessons learned were derived from including low literate persons in the user-centered design process. The guidelines should be made available to ICT developers and, when applied properly, will contribute to the advancement of (health) literacy and empower citizens to fully participate in society.

INTRODUCTION

People in modern western information societies are expected to become more and more self-reliant and experience increasing demands of proactivity and problem-solving ability [1, 2]. However, large groups, in particular people with low literacy, lack the necessary skills to do so. In the Netherlands, the level of literacy of approximately thirteen percent of the adult population is too low to be able to function adequately in society [3]. Besides low literacy, this group generally also suffers from low numeracy and low problem solving skills, which are considered the three core skills needed for societal participation. Literacy is defined as the use of printed and written information to achieve personal goals and to develop personal knowledge and skills. Prose and document literacy refer to two aspects of literacy. Prose literacy is similar to the 'classical' view of literacy; the knowledge and skills required for reading, understanding and applying longer pieces of text, such as letters, news items, brochures and manuals. Document literacy refers to 'concentrated' text types, such as admission forms, paychecks, public transport time schedules, maps, tables and graphs. Numeracy is the knowledge and skills that are necessary to effectively deal with numbers in various situations, for example counting money, understanding proportions, percentages, statistical information, tables and graphs. Problem solving skills involve thinking and acting in situations with a reasonably well-defined goal, though no available routine solutions. The problem solver needs to be able to understand the problem situation and change it through planning and reasoning [3].

One specific problem area where all three skills are relevant is filling in forms and questionnaires, which are omnipresent in all societal domains where self-reliance is advocated. Being able to fill in forms and questionnaires is a prerequisite for, for example, meeting legal obligations (e.g. tax forms), making use of services (e.g. health care), ordering products, filing complaints and voicing one's opinion (e.g. voting). Forms, whether offered on paper or digitally, are usually text-oriented and presented in a concentrated format which is hard to grasp for low literate persons. In particular document literacy skills are relevant in this respect. Numeracy is required, e.g., for understanding scales with answer possibilities, such as Likert scales or grades. Problem solving skills are needed for understanding the rationale for filling in the questionnaire, the nature and relevance of one's input (e.g.,

factual information, questions, complaints or ideas) and translating these into the format of the questionnaire.

Problems with forms and questionnaires could be potentially alleviated by taking advantage of the possibilities of information and communication technology (ICT), for example by offering alternatives to text (e.g. audio, pictures, movies), self-explanatory scales and easily accessible background information on the questionnaire's rationale. This requires comprehensive guidelines for designing interactive forms and questionnaires. Also, in order to make sure that resulting ICT solutions indeed fit the needs and possibilities of low literate persons, representatives of the target group should be closely involved in the design and evaluation process (user-centered design). This process may also result in an update of current guidelines.

The goal of this paper is to present explorative design guidelines for developing interactive questionnaires for low literate persons. The guidelines are derived from a user-centered design process of the Dutch Talking Touch Screen Questionnaire (DTTSQ). The DTTSQ is an interactive health assessment questionnaire used in a physical therapy setting. Standardized health assessment using questionnaires is important for self-reliance, since it improves patient-provider interaction by facilitating the patient's input into the healthcare process [4, 5]. The DTTSQ was inspired by existing foreign talking touch screens [6-11]. These touch screens had already been developed for persons with low health literacy, meaning they have problems with seeking, understanding and using health information [12]. This group mainly exists of low literate persons. The user-centered design process has resulted in a working prototype of the DTTSQ, running on a touch pad. The resulting explorative user interface design guidelines can be applied to developing digital forms and questionnaires for low literate persons in other domains.

The paper first presents a model of the problems of low literate persons and ways to alleviate these problems in the design of technology in Section 2. Then, the specific problem area of filling in health assessment questionnaires in the context of health literacy is discussed in Section 3. Section 4 describes the user-centered design process of the DTTSQ. Explorative guidelines resulting from this process are presented in Section 5, according to the model aspects of

Section 2. Finally, in Section 6, conclusions from the current work and suggestions for future work are provided.

2 Low literate persons and ICT use

Low literate persons lack sufficient reading, writing and calculation skills which are needed to function successfully in society. In addition, they lack the skills necessary to work with machines, understand instructions and use information and communication technology (ICT) [13]. Problems and (lack of) abilities of low literate persons as well as aspects of the product/service that should be designed to support the target group and alleviate the problems can be visualized in a model presented in Fig. 3.1 These problems can be alleviated in the design of an ICT product or service. The model forms the basis for formulating guidelines for designing ICT for this target group [14].

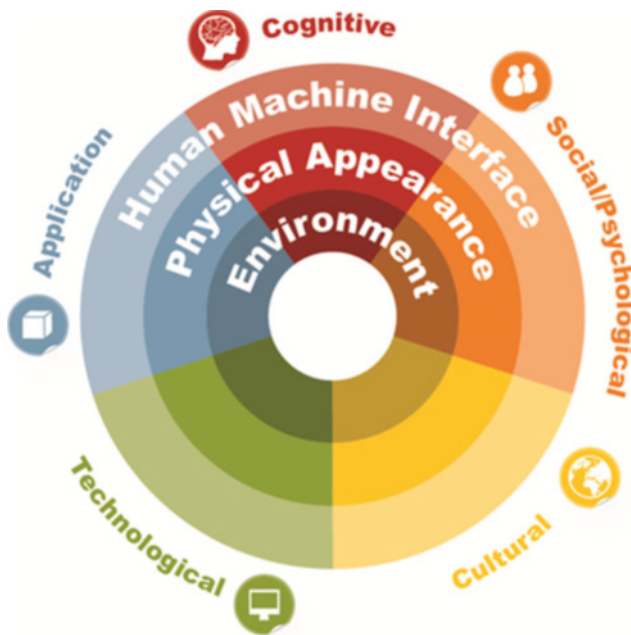


Figure 3.1 Problem areas of low literate persons relevant for ICT use (Cognitive, Social/Psychological, Cultural, Technological and Application), and their implications for ICT design (Human Machine Interface, Physical Appearance, Environment)

The five main problem areas for low literate persons are cognitive, social/psychological, cultural, technological and application-related. They are briefly described as follows:

- Cognitive problems refer to the aforementioned literacy, numeracy and problem solving skills. They include reading, writing, listening, calculation, visual organization and memory, speed of cognitive processing, mental spatial orientation, vigilance and multi-tasking. An example guideline is:

"Provide spoken language as an alternative to written text. Spoken language can either be natural speech or text automatically converted to speech by using speech synthesis software, which is particularly useful for unpredictable or dynamic texts. However, natural speech may be preferable since it is less distracting."

- Social/psychological problems occur mainly due to the lack of self-efficacy [15] and stress low literate persons experience using a product/service in a public place. An example guideline is:

"The system should not stigmatize users. Design the user interface in such a way that the fact it was designed for illiterate persons is not too obvious or visible to others. Preferably design an interface that is easy to use for users with all levels of literacy."

- Cultural problems may be different in different countries/cultures, leading to different solutions. An example guideline is:

"Take into account that mental models about technology may be different between cultures."

- Technological problems low literate persons encounter include computer anxiety; they perceive a computer as being complex and impersonal, leading to fear of making mistakes they cannot correct anymore. An example guideline is:

"The physical appearance of the product or service should be appealing to the user. The interface should have a personal, inviting, simple and non-technical look."

- Application domain-specific problems may occur, for example lack of health literacy may play a role when using a health assessment questionnaire. An example guideline is:

"Do not use specific health-related terms in the questionnaire, which illiterate persons may not understand."

The ICT product/service aspects that may alleviate the aforementioned problems are the human-machine interface, the physical appearance of the product/service and the environment in which it is being used:

- The human-machine interface involves the interaction of the user (operation) and the product/service. An example guideline is:

"The human machine interface should be inviting and intuitive."

- The physical appearance involves the look-and-feel of the product/service (mainly hardware). An example guideline is:

"The physical appearance should be friendly and trustworthy."

- The environment involves the social and physical context in which the product/service is located. An example guideline is:

"The environment should provide sufficient privacy."

3 Health literacy and assessment

3.1 Health literacy

One of the areas in which self-reliance is particularly relevant is health care. Since alliance between health care professionals and their patients correlates with better treatment outcomes [16], patients are expected to take a more active, mutual, partnered part in the patient-provider relationship. To do this effectively, patients need to be health literate, meaning they need to be able to seek, understand and use health information [12]. However, large groups in society, in particular people with low literacy, lack the necessary skills to do so [12, 17-19].

People with limited health literacy have little knowledge about their own health conditions [19], which has broad ramifications on how they interact with their health care providers. Patients with poor health literacy skills have trouble determining what information their providers need and what information is irrelevant. They often lack the health care vocabulary to report symptoms accurately and may convey information illogically or in a jumbled order [17]. Low literate patients often feel overwhelmed by information about their illness and tend to ask fewer questions [17]. The tendency to be more passive complicates patient-provider interaction further and leads to miscommunication [20]. This may cause poorer understanding of illness and treatment, poorer health status, less understanding and use of preventive services, and increased hospitalizations [21].

3.2 Health assessment questionnaires

Standardized health assessment using questionnaires improves patient-provider interaction by facilitating the patient's input into the healthcare process [4,5]. A re-port of the status of a patient's health condition that comes directly from the patient without interpretation of the patient's response by a clinician or anyone else helps to assess the burden of disease and treatment from the patients' perspective [22].

However, it can be assumed that using traditional paper-based questionnaires in a low literate patient population will not contribute to patient-provider interaction. In fact it may complicate the situation further. Possible mistakes made by the patient in completing the questionnaire may lead to invalid information. Moreover, the burden of having to complete a task which is hard to fulfil can lead to emotional strain, which makes it even harder for the patients to maintain themselves in the complex context of a health care setting.

Previous research in the USA, India and China has shown that smart deployment of ICT increases the ability of low literate patients to independently fill in health-related questionnaires [7-10,16], even if patients had limited or no computer skills [11]. These so-called Talking Touch Screens (TTS) added visual (pictures, videos) and auditory (speech) support to multiple choice questions which were shown one by one on a touch screen. In this way patients were able to see and hear the questions and accompanying visual materials. The patient responded to the questions by tapping the preferred answer on the touch screen.

Although effects on patient-provider interaction of these TTS's have not been established yet, all findings so far indicate that they do increase the usability of questionnaires for low literate patients [6-11, 23-25]. However, the potential of such tools might be increased by systematically taking into account evidence-based knowledge on designing smart support for self-reliance of low literate persons. Also, differences in the health care system as well as language and cultural differences between, on the one hand, the USA, India, China and, on the other hand, The Netherlands should be considered.

4 Development of the DTTSQ

4.1 Method: user-centered design

User-centered design was applied during the development of the

DTTSQ (see Fig. 3.2) [26]. The essential characteristic of this method is that it involves users that belong to the target group (in this case low literate persons) of an envisioned product or service in all phases of the development process, and as early as possible. Starting from existing knowledge on man-machine interaction (MMI) theory, guidelines and methods and the envisioned technological design space (system and task demands), user interface specifications are drafted, evaluated and refined in iterative phases of development. The user-centered design method consists of three main phases: analysis, design and implementation. In the analysis phase, on the basis of characteristics of the users, their goals, their information and support needs and the use context, the functions of the system and the associated information are determined (user interface design at the task level). In the design phase, the operation of the functions and the information presentation are specified (user interface at the communication level). In the implementation phase, the user interface design is implemented.

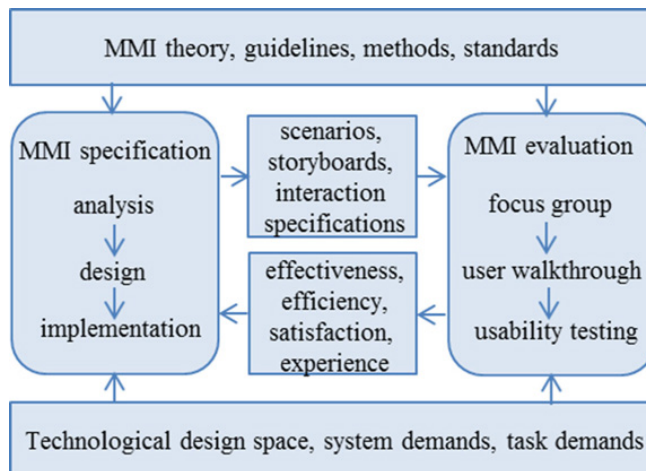


Figure 3.2 User-centered design: Man-machine interaction (MMI) theory, guidelines and methods, technological design space, system and task demands, iterative phases of development (analysis, design and implementation), user interface specifications (scenarios, storyboards, interaction specifications), MMI evaluation (focus group, user walkthrough, usability testing) and evaluation outcomes (effectiveness, efficiency, satisfaction, experience)

4.1.1 MMI theory, guidelines, methods and standards:

To develop the DTTSQ, existing guidelines that are relevant for designing for low literate persons have been applied. These range from 'Design for All' guidelines for ICT products and services [27] to guidelines for simple communication [28,29]. Specific guidelines for the target group of the present study include simple text, speech, icons that are easily recognizable, and combinations of text, speech and icons [31-33]. Simple text refers in particular to the wordings of the original paper-based questionnaire.

4.1.2 Technological design space:

The most frequently applied paper-based questionnaire in Dutch physical therapy [33], the Patient-Specific Complaints questionnaire (PSC) [34], was taken as a starting point for the design of the DTTSQ. The current PSC consists of four sections. In the first section the patient is asked to select from a long list of activities all activities that have become problematic because of complaints, and/or add other activities. In the second section the patient is asked to select five activities out of the initial selection that should be improved with physical therapy. In section three, the patient should select and prioritize the three most urgent activities. In section four, the patient has to rate the current effort needed to carry out these three activities on an 11-point numeric rating scale (0–10; 0 stands for no effort at all and 10 for all effort imaginable).

The design team has chosen a touch pad as the best suitable device for a Talking Touch Screen. The lack of privacy and security that using speech output may bring along is handled by providing users with headphones.

4.1.3 User involvement:

User involvement in developing the DTTSQ was organized through two focus group sessions, two user walkthroughs and a usability test with the target group of low literate persons. In a focus group session, a small, carefully selected group of people is brought together for an interactive and spontaneous discussion on user needs and opinions around a certain subject or concept. Focus groups are on the one hand informal, though on the other hand controlled through questions posed by a facilitator. Outcomes are a rich picture of the users, and initial user requirements for the system. During a user walkthrough

sketches, storyboards, user interface specifications or interactive mock-ups are evaluated. This may take the form of the users exploring the design individually while giving comments about problems and possible improvements. Alternatively, the facilitator may ask the users to carry out tasks. This provides insight in the mental model of the users, their expectations, strategies, thoughts, emotions and opinions, but also terminology used to talk about functions. Outcomes are prioritized bottlenecks and suggestions for improvement. During usability testing users carry out predefined use scenarios (tasks) with the prototype individually. Their behaviors and tasks performance are recorded and judged by usability experts. Subjective information is gathered through questionnaires or interviews. Usability testing makes it possible to evaluate the system in terms of effectiveness, efficiency and satisfaction [26].

User involvement with low literate persons poses some specific considerations [35]. To accommodate this group, all methods were adjusted in order to avoid offering information or asking questions in written form and requiring participants to respond in the same manner [31,13]. Also, since low literate persons are often ashamed of their limitations and insecure about their abilities [36], it is important for them to be in a familiar environment within a group of like-minded people who trust each other, in a relaxed atmosphere [37]. Researchers should devote ample time to introducing themselves, managing expectations and taking away possible considerations and worries. Also, participants should be rewarded for participation.

4.2 Participants: low literate persons

A group of ten adult native students of a basic reading and writing course in Amersfoort, The Netherlands, was approached through their teacher for participation. These people had already acknowledged their problems by attending the course and the associated admission exam and had become familiar with each other. They had also established a relationship with the teacher whom they appreciated and trusted. Consulting them as a group made them the majority within the setting, which seemed to empower the participants.

The teacher played an important role during the various sessions, all of which she attended. The fact that the teacher trusted the researchers, their methods and the way they handled the information provided by

the participants was reassuring to the participants. Furthermore, she helped the researchers to present the information and questions in a way that was manageable for the participants. She guarded fatigue levels of participants carefully and intervened when necessary. Finally, she made sure participation in the research project contributed to the learning objectives of the course, so that it would not slow down the learning process of the students.

Prior to participating in a health research project, people are required to sign an informed consent form with information on the project, indicating they are well informed and aware of the implications of participation. The informed consent form used was written in simple and clear language by a specialized writer. It was handed out during a course session, explained by the teacher, and the students helped each other to understand it. In a following course session the researchers took the time to make sure all students had understood the information and were able to make an informed decision whether or not to participate. After all students had agreed to participate, the project was made part of the course so that it did not cost them additional time. At the end of the project each participant was paid 10 euros per session.

4.3 Procedure

4.3.1 Analysis phase:

Two focus group sessions. The goal of the first focus group session was to get a better idea of participants' experiences with and opinions on forms and questionnaires in general, and health-related forms in particular. Six students (1 male, 5 female) participated. The session was facilitated by a health scientist, two interaction designers and the course teacher, and lasted for two and a half hours. The students were first asked to talk about their experiences with filling out forms and questionnaires in general. Which forms do they perceive as easy to fill out and which forms not? What needs do they have according to the language that is used, the structure of the form and the context in which the form needs to be filled out? Additionally the researchers drew the scenario of filling out forms within a health care setting and asked the students to comment on that. Finally, the students were asked to comment on the existing paper questionnaire (PSC).

During the second focus group session participants were asked to comment on first ideas (sketches) drawn on the basis of the needs

that were expressed during the first session. Seven students (2 male, 5 female) participated. The session was facilitated by two health scientists, an interaction designer, two software developers and the course teacher. The session duration was two and a half hours. In particular, the items of the questionnaire, the order of the items and the need for support were discussed.

4.3.2 Design phase:

Two user walkthroughs. The goal of the first user walkthrough was to get feedback on different designs on the number and the order of questions and different forms of support (when and how). Of the eight persons who participated, four were asked two by two to give feedback on different visuals of potential designs to determine what functionalities and 'look and feel' they preferred. The other four were asked two by two to give feedback on different scenarios considering the order and number of steps in which questions were asked.

During the second user walkthrough, six participants were asked to give feedback on a click-through mock-up version of the DTTSQ. The goal of this session was to see if earlier information given by the users was interpreted correctly and transferred adequately to the design of the DTTSQ.

4.3.3 Implementation phase: usability testing. Based on results of the user walkthroughs, the design of the DTTSQ was created and implemented on a touch pad (see Fig. 3.3 for a screenshot of the help function and buttons; an overview of final DTTSQ screens is provided in Fig. 3.4 - Fig. 3.9). The usability of this version of the DTTSQ was tested by four students who had not taken part in earlier sessions. Each participant was asked to use the DTTSQ individually and autonomously and to meanwhile think aloud. Two researchers observed the actions of the participants and made notes on how they used the DTTSQ. Afterwards, the researchers discussed their observations and questions with the participant. Then, they asked the participant to give his/her opinion on the usability of the DTTSQ and to give suggestions for improvement. Finally, participants were asked to also test functionality that had not been used spontaneously, in particular the help function.

All four participants were able to fill out the DTTSQ autonomously in approximately 5 minutes, which was fairly acceptable to them. Three of them used the read aloud function. They used neither the help nor the escape functions. Two users indicated they had missed a back function. The help function was hard to understand for the participants. All screens contained a help button, which activated an overlay of the current screen. The overlay provided written information and instruction, an explanation of all the buttons on the screen, and a movie of a host providing spoken information and instruction. Participants were confused by the multitude of information. Also, they did not understand that the overlay was not interactive and that they had to return to the original screen in order to carry out the instruction. Participants did not use the escape function, since they did not understand the meaning of the symbol that was chosen for this button (an exclamation mark in a triangle). However, all users appreciated the function and advised to use a traffic stop sign instead.



Figure 3.3 Help function as an overlay to the current screen, with written information and instruction, explanation of buttons, and access to a movie of a host (movie icon, bottom left). Top right: read aloud button and help button. Bottom left: escape button (triangle with exclamation mark)

Implementation phase: final design. On the basis of the usability evaluation the final design of the DTTSQ was created (see Fig 3.4- Fig. 3.9 for a selection of screens). The original help function was deleted and the read aloud function was turned into a help function. The help button

activates a spoken explanation of the current screen, during which all functions remain active. Both the text on the screen is read aloud and additional information and instruction are provided. Further, all screens have a stop button (the original escape function was turned into a traffic stop sign) and a forward button. A back function was not added.

On entering the DTTSQ, an instruction movie is played (Fig. 3.4). Then, in the first part the patient has to answer the question whether or not he/she experiences pain (Fig. 3.5). If he/she experiences pain, he/she can indicate the location(s) of the pain (Fig. 3.6). For every location, he/she can indicate the severity of the pain on a scale (1-10) (Fig. 3.7). Then, the DTTSQ offers an overview of all answers given so far. In the second part the patient can select activities in various categories presented on separate screens which are difficult because of current complaints (Fig. 3.8). Following all activity screens, the DTTSQ presents an overview of all selected activities so far. Then the patient has to select the three activities that are the most difficult to perform because of current complaints. On the screen that follows, the patient has to put the three activities in order of priority. For the three activities he/she has to indicate the difficulty in performing these activities on a 1-10 scale. Then the DTTSQ offers an overview of all answers given by the patient (Fig. 3.9). Finally, a goodbye movie is played explaining what is going to happen next.

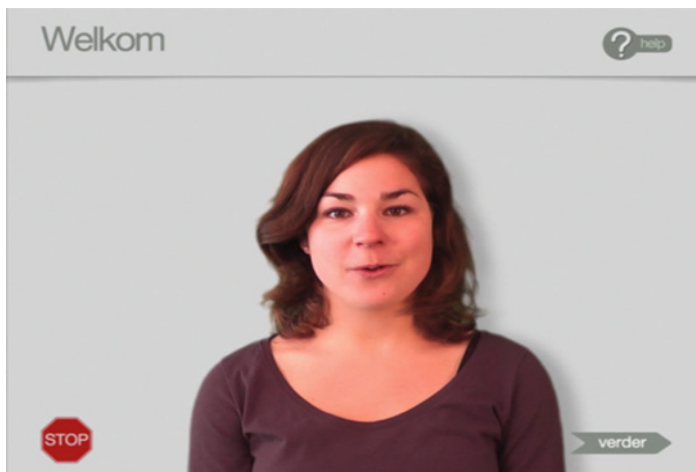


Figure 3.4 Welcome screen: instruction movie, help, stop and forward buttons



Figure 3.5 Do you have pain?: Yes (red), No (green)



Figure 3.6 Location of complaints: Press all body locations where you have complaints



Figure 3.7 Pain severity: Indicate how much pain you have at this body location (1-10)



Figure 3.8 Activities (Personal care): Press activities that cause complaints. Press white arrow to scroll for more activities



Figure 3.9 Overview of all answers: locations of complaints, important activities and severities

5 Guidelines for interactive questionnaire design

The following explorative guidelines were derived from the final design of the DTTSQ. This final design was accomplished through an iterative process where all feedback and ideas of participants were used in consecutive designs. If there was no consensus, alternative design versions were created. Iterations were carried out until strong consensus among the participants was reached. Ultimately, the design was tested with a new group of participants, which led to some final minor alterations, indicating the design was suitable for low literate users.

The guidelines are categorized according to the model presented in Section 2. If available, relevant quotes of participants are provided.

5.1 Cognitive

5.1.1 Information overload:

Avoid users feeling overwhelmed with information. Avoid questions that have difficult wording, that are too similar or too personal.

Quotes:

"If you leave a question open because you don't understand it or because you don't want to answer it, the form is always returned to you with the remark that you forgot to answer the question; "Forms that have to be filled out for taxes, health insurance, getting a divorce, getting welfare services, it is all so hard. And if you make a mistake you are in big trouble!"

"I filled out a questionnaire of fifty questions. After that I was phoned by numerous companies. I didn't read the policy well. I will never fill out a questionnaire again!"

5.1.2 Complex instructions:

Do not make instructions complicated and long. Do not use difficult words.

5.1.3 Open questions difficult:

Do not use open questions. Instead use multiple choice or check marks, because reading is easier than writing.

Quote:

"I won't fill out such a question. I am afraid to make a fool of myself"

5.1.4 Problems with scales:

Scale of 0-10 for numeric rating scales are understandable. However, take into account that translating feelings into numbers is hard, and not knowing how the health care professional will understand the number creates uncertainty.

5.2 Social/psychological

5.2.1 Personal characteristics:

Take into account that negative feelings towards forms may be strengthened by personal characteristics of low literate persons, such as being unsure, having low self-esteem and doubting their own

judgment.

Some quotes:

"People who have low self-esteem might be too modest about themselves in their answers. If you are very doubtful, which we all are, choosing the right answer is nerve wrecking."

"When I have trouble filling out forms I always put the blame on myself. I want to be able to participate, like everybody else. It makes me very sad."

5.2.2 Emotional problems:

Take into account that in a health setting users may feel emotional, which strengthens the stress of having to fill in questionnaires.

Quote:

"When I am sick and feeling emotional it is even harder for me to read and write."

5.2.3 Impersonal, but the only way to get things done:

Take into account that users may feel forced to fill out the form, because otherwise they are not able to get the products and services they need. They think of forms as impersonal which makes them feel being treated as a 'number'. They feel that making people fill out questionnaires is a way for professionals to diminish their responsibility and the risk of being blamed if things go wrong. They prefer to talk to a person and to just 'say what you mean'. Quotes:

"Do you know why people are getting ill? Because they get too little attention from other people! People don't feel noticed anymore. This is getting worse by all the questionnaires and telephone menus that are being used nowadays. People just want to be able to speak to a real person!"

"How impersonal! Doctors just need to listen and watch carefully. Can't we get health insurance companies to give us more time?"

5.3 Technological

5.3.1 Unfavorable consequences of errors:

Take into account that users may feel that depending on the results they get a label and are put into a category. When you put your name and signature on the paper you will never be able to get rid of that label even if that label does not fit you.

Quotes:

"To avoid getting a 'bad label' I am not always honest when I fill out questionnaires or forms."

"When I give out wrong information because I didn't understand the questionnaire right they say: but you have said so yourself."

"I had to fill out a questionnaire about my children. After that child protection contacted me. I must have made a mistake in filling out that form. Now, years later, they are still monitoring me."

5.3.2 Problems with computer use:

Take into account that users may have problems filling out a questionnaire on a computer.

5.4 Application

5.4.1 Help for diagnosis:

Take into account that users put a lot of faith in health-related questionnaires.

Quote:

"I have been ill and it took years for doctors to find out what was wrong with me. If a questionnaire could have helped to speed up the process I would have wanted them to use it."

5.5 Human-machine interface

5.5.1 Text and font

5.5.1.1 Simple language:

Use plain language and short sentences.

5.5.1.2 Read aloud text with speed adjustment:

The speed at which text is spoken should be adjustable. The text that is being read should change in color like karaoke lyrics to make it easier to read along with the spoken text.

5.5.1.3 Additional information in spoken text:

The spoken text should, in some cases, contain more text than is written on the screen. For instance when the answer option contains two buttons of different colors, the read out loud text should describe the color of the buttons and their functions, so illiterate users will also be able to fill out the form.

5.5.1.4 Font:

The font should be as large as possible for readers who have visual problems.

5.5.2 Scales

5.5.2.1 Show only relevant items:

Do not add words or metaphors (smileys, thermometer, thumbs up) to the scales.

5.5.2.2 Discrete scales:

The numeric rating scale should contain absolute figures as opposed to an ongoing scale.

5.5.2.3 Use of color:

Coloring numbers (from green for non or not severe to red for severe) would make it easier to find the right answer.

5.5.3 Illustrations and photographs

5.5.3.1 Pictures and icons:

Use pictures and recognizable icons to enhance comprehensibility.

5.5.3.2 Concrete:

Illustrations should be as concrete as possible.

5.5.3.3 Show only relevant attributes:

Do not show irrelevant attributes in foreground or background. The background of the photographs should be white.

5.5.3.4 Consistent:

All illustrations should have the same look. They should all show the same person.

5.5.3.5 Photographs better than illustrations:

If possible, use photographs instead of illustrations.

5.5.4 Structure and lay-out

5.5.4.1 Minimize number of functions:

Minimize the number of functions and buttons.

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5.5.4.2 Consistent screen lay-out:

Each screen should have the same functionalities and look the same.

5.5.4.3 Show only relevant items:

Avoid unnecessary distracting functions, text, illustrations.

5.5.4.4 Clearly recognizable buttons:

The buttons in the screen should be recognizable and big enough to be seen clearly on the screen. The form of the button should symbolize its function. The 'forward-function' should be in the form of an arrow that points 'the next screen'.

5.5.4.5 Limited number of items to choose from:

Not more than three items (for example photographs) should be shown on a screen at the same time. If more options are available, add a scroll function to show the remaining items.

5.5.4.6 One question per screen:

Show only one question per screen.

5.5.4.7 Feedback:

When a button is activated it should be accentuated.

5.5.5 Navigation

5.5.5.1 Not too long:

Make the questionnaire as short as possible.

5.5.5.2 No progress indication:

Do not use bookmarks, index or page numbers to indicate the progress. This adds to the pressure and distracts the user from the question.

5.5.5.3 No 'back' function:

Do not use a 'back'-function, because it gives users the feeling they could get lost within the questionnaire. Users just want to be able to go forward.

5.5.5.4 Provide overviews:

Add regular overviews so that mistakes in answering are identified at an early stage, and allow correction. An overview could consist of pictures and images selected earlier. In this way, a back function is not

necessary.

5.5.5.5 Stop button:

Use an 'escape button' which makes it possible to stop filling out the questionnaire at any time.

5.5.6 Support

5.5.6.1 Introduction:

The introduction should be a movie of a host explaining the questionnaire. It should cover the following topics:

- goal of the questionnaire;
- handling and privacy of personal data;
- reassurance that there is no time pressure;
- reassurance that answers can be adjusted even after the questionnaire is finished.

5.5.6.2 Instruction:

The instruction should be a movie by the same host as the introduction. It should contain the following information:

- answering is possible by tapping on the touch screen;
- all functionalities / buttons of the DTTSQ need to be explained briefly;
- the button that is being explained during the animation should be highlighted (by temporarily changing the color of lines of the button, not by moving objects on the screen).

5.6 Physical appearance

5.6.1 No keyboard:

Do not use a keyboard for input.

5.6.2 No computer appearance:

It should not look like a computer.

5.6.3 Not too small:

It should not be as small as a smartphone, because of the small screen and limited legibility.

5.7 Environment

5.7.1 Only use if really necessary:

Do use questionnaires only if it is really necessary.

5.7.2 Relaxed atmosphere:

Create a relaxed atmosphere where people are comfortable, where there is no pressure (in time or other persons present) to fill out the questionnaire, where they can fully concentrate, their privacy is guaranteed and create trust that information provided is treated with care.

5.7.3 Explain goal and content:

Provide an explanation of the goal and content of the questionnaire, and clear instructions on how to fill it out.

5.7.4 Discuss results with a health professional:

The questionnaire needs to be discussed afterwards to make sure no mistakes were made and both the patient and the health care professional interpret the questions and answers in the same way. This creates shared responsibility about the content and results of the health care process.

5.7.5 Correction possibility:

Provide the possibility to adjust answers, even after the questionnaire has been filled out and handed over to the professional.

6 Conclusions and further work

The goal of this paper was to present explorative design guidelines for developing interactive questionnaires for low literate persons, derived from the design of the Dutch Talking Touch Screen Questionnaire. It has proven possible to derive a decent number of guidelines and present them according to an existing, comprehensive model. Also, lessons learned were derived from including low literate persons in a user-centered design process. Apart from the multi-disciplinary development team, including the course teacher, the input of the low literate participants has proven to be indispensable for the design of the ultimate DTTSQ.

The latest version of the DTTSQ, including the suggested improvements presented in Section 4.3, will be tested in a Dutch physiotherapy practice by patients with low, medium and high education. Also, translations of the DTTSQ into other languages will be made and evaluated, starting with Turkish, taking into account cultural differences between Dutch and foreign patients. In addition, they will provide new guidelines, for

example about cultural aspects of the design. This study will provide valuable insight into the added value of the interactive questionnaire over a regular paper questionnaire for low (health) literate persons and possibly other groups.

The guidelines can be applied to other questionnaires for the low literate user group, within and outside of the physiotherapy or even medical domain. Moreover, since similar problems are experienced by other groups in society, in particular people with cognitive limitations of various kinds, the guidelines may be applicable to these groups as well. A lot of research has already been carried out into various target groups and applications, which has resulted in lists of design recommendations and guidelines. For example, design principles for elderly people [38], for children [39] and design considerations for people with cognitive disabilities [40, 41] are available for use [42].

In order to investigate whether available guidelines are interchangeable, the proposed model of cognitive, social/psychological, cultural, technological and application-related problems of low literate persons (Fig. 1) should be extended to encompass specific problems of these other target groups. For example, specific cognitive problems of elderly people could origin from loss of memory, children may have attention problems and people with cognitive disabilities may have problems with multi-tasking. By presenting the guidelines as possible solutions to alleviate specific cognitive problems when using an ICT system, they can be applied to multiple user groups who experience these problems. The same approach applies to the model's other problem categories. Further, guidelines may or may not apply to other types of applications, depending on the functionalities they offer. Aside from actual application-specific guidelines, care should be taken to formulate guidelines in a non-application-specific manner, to allow transferability to other applications.

The current guidelines should already be made available to developers of interactive questionnaires, and will contribute to the advancement of (health) literacy, empowering citizens (low literate persons, but most probably also other groups) to fully participate in society.

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CHAPTER 4

Evaluation of the Dutch and Turkish version of the Talking Touch Screen Questionnaire



4.1

Using plain language and adding communication technology to an existing health related questionnaire to help generate accurate information: qualitative study.

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ABSTRACT

Background

Low-educated patients are disadvantaged in using questionnaires within the health care setting because most health-related questionnaires do not take the educational background of patients into account. The Dutch Talking Touch Screen Questionnaire (DTTSQ) was developed in an attempt to meet the needs of low-educated patients by using plain language and adding communication technology to an existing paper-based questionnaire. For physical therapists to use the DTTSQ as part of their intake procedure, it needs to generate accurate information from all of their patients, independent of educational level.

Objective

The aim of this study was to get a first impression of the information that is generated by the DTTSQ. To achieve this goal, response processes of physical therapy patients with diverse levels of education were analyzed.

Methods

The qualitative Three-Step Test-Interview method was used to collect observational data on actual response behavior of 24 physical therapy patients with diverse levels of education. The interviews included both think-aloud and retrospective probing techniques.

Results

Of the 24 respondents, 20 encountered one or more problems during their response process. The use of plain language and information and communication technology (ICT) appeared to have a positive effect on the comprehensibility of the DTTSQ. However, it also had some negative effects on the interpretation, retrieval, judgment, and response selection within the response processes of the participants in this study. No educational group in this research population stood out from the rest in the kind or number of problems that arose. All respondents recognized themselves in the outcomes of the questionnaire.

Conclusions

The use of plain language and ICT within the DTTSQ had both positive and negative effects on the response processes of its target population. The results of this study emphasize the importance of earlier recommendations to accompany any adaption of any questionnaire to a new mode of delivery by demonstrating the difference and equivalence between the two different modes and to scientifically evaluate the applicability of the newly developed mode of the questionnaire in its intended setting. This is especially important in a digital era in which the use of plain language within health care is increasingly being advocated.

INTRODUCTION

Background

It is widely known and accepted that patient-centered care has the potential to increase the effectiveness of health care in general [1]. Unfortunately low-educated patients are not always able to benefit from a patient-centered care approach. A possible explanation for this can be found in the fact that patient-centered care demands of patients to take an active mutual partnership in the patient-provider interaction [2,3]. Patient-centered care puts a relatively strong emphasis on communication and information and takes the patient's perspective as a starting point [4,5]. Low-educated people have trouble providing information about their health problems to health care professionals. It is often hard for them to determine which information their health care provider (HCP) needs. The majority of them lack the health care vocabulary to report symptoms accurately, and they tend to provide information in a way that is illogical and difficult to comprehend by their HCP [6]. Having trouble providing information causes problems in patient-provider interaction, which impacts health outcomes negatively [7]. Evidence shows that the use of standardized health-related questionnaires contributes to the quality and patient centeredness of patient-provider interaction [8-13]. However, as most health-related questionnaires are not designed in ways that meet the needs of low-educated patients, these patients are disadvantaged in using them effectively within the health care setting [11-13]. In 2016, 9.5% of the Dutch population in the age range of 15 to 75 years had an educational level of primary school at most [14]. These people specifically are at risk when it comes to understanding and using

health information [15]. If low-educated patients would be able to complete standardized health-related questionnaires independently and accurately, this might help them to provide relevant information on their health problem in a way that is logical and understandable to their HCP.

The content of the most frequently used questionnaire in Dutch physical therapy practice [16], the Patient Specific-Complaint (PSC) questionnaire [17], fits the goal of helping patients to provide relevant information regarding their health problem to their physical therapist. It is aimed at making the patient select his main limitations in functioning and formulate his own specific treatment goals. This paper-based questionnaire is responsive and sensitive to change to complaints that are highly relevant to the individual patient [17,18]. However, all members of the Dutch study sample of a recent study on the PSC questionnaire had problems completing it independently. All these 25 respondents, whose education levels varied from primary education to doctoral degrees, had trouble comprehending and interpreting one or more parts of the questionnaire. Six of them had difficulties finding a well-fitting answer to one or more questions. Due to these problems, the questionnaire generated invalid information in thirteen cases. Within the group respondents who provided invalid information, patients with no or primary education only were overrepresented [19].

The Dutch PSC questionnaire [17] was used as a starting point for the development of a user-friendly health-related questionnaire that meets the needs of low-educated physical therapy patients. This aim was met by using plain language and taking advantage of the possibilities of information and communication technology (ICT) by offering alternatives to text (e.g., audio, pictures, and movies), self-explanatory scales, and easily accessible background information on the questionnaire's rationale. This resulted in the prototype of a new interactive questionnaire called the Dutch Talking Touch Screen Questionnaire (DTTSQ). The co-design process that led to the development of this prototype was described in detail by Cremers et al in 2015 [20].

Objective

The aim of this study was to get a first impression of the validity of

the prototype of the DTTSQ by analyzing the response processes of patients with diverse levels of education. The research question that underlay this study was, "What problems occur during the response process of physical therapy patients with diverse levels of education while they complete the Dutch Talking Touchscreen Questionnaire?"

METHODS

4.1

Design

A qualitative study was conducted. The Three-Step Test-Interview (TSTI) method [21] was used to collect observational data on actual response behavior of the respondents. The interviews included both think-aloud and retrospective probing techniques. Qualitative pretesting of questionnaires using cognitive methods such as the TSTI [21] is a well-known step within the development process of health-related questionnaires [22-25]. It enables researchers to give answers to questions such as the following: do all respondents understand the questions in the same way, do the questions ask for information that the respondents have and can retrieve, and does the wording of the questions provide respondents with all necessary information they require to be able to answer them in the way that was intended by its developers [22]?

Device

The DTTSQ was developed during a user-centered design process [20], which meant that low-educated persons were closely involved in designing the questionnaire. As a result, questions about pain location and pain intensity were added to the original questions that addressed the nature and severity of limitations in activities of daily living and the priority in which these limitations should be focused on during physical therapy. Needs regarding ease of use were met by the use of visual (pictures and videos) and auditory (speech) support, which was added to the questions. Respondents could insert their answers by tapping on the touch screen. The DTTSQ started with an introductory video clip in which a host explains the purpose of the questionnaire and gives instructions on how to use the questionnaire (see Appendix 1: 1."Welcome"). All the questions were shown on separate screens. The application did not have a back function, so respondents could only move forward. After the first three questions, a new clip was shown to introduce and operationalize the term "activities" and to give

instructions on an additional navigation function within the activity screens (see Appendix 1: 6. "Activities"). The questionnaire finished with a video clip in which the host thanked the respondent for completing the questionnaire, explained what the physical therapist would do next, and announced that the questionnaire would end and close down automatically (Appendix 1: 16. "Thank you"). To help patients keeping track of their answering process, overviews of their answers were shown regularly during the response process (see Appendix 1: 5. "Overview location of the health problems", "Overview activities", "Overview most important activities", "Overview most important activities and effort", "Overview all outcomes of the questionnaire"). For respondents who needed help or wanted more information on questions and/or answer options, a help function was provided. When the help function was activated, the question and answer options, as well as instructions on operation and background information on the questions, were given in spoken word [20].

Recruitment Strategy and Participants

Recruitment took place in eleven primary care practices in deprived areas of Utrecht, The Netherlands. Potential participants were invited by their physical therapists to participate in this study. The physical therapists shortly explained the goal of the study and provided the patient with an information letter that was written in plain Dutch language. If patients were interested, the physical therapist asked permission to give the patients' telephone number to researcher IT. Then researcher IT (1) Contacted the patient by telephone, (2) Again shortly explained the aim of the study, (3) Made sure the patient understood what was asked of him/her, (4) answered any question the potential participant may have had, and (5) Checked the inclusion criteria. Inclusion criteria for participants were as follows: aged 18 years or older, Dutch as their first language, and both parents born in The Netherlands. The sampling procedure was aimed at getting a broad variation in levels of education and age, plus balance in our sample regarding gender. Throughout the recruitment process, the recruiting physical therapists were constantly kept informed about the profiles of participants the researchers were looking for. In total, 24 physical therapy patients were included in this study. Characteristics of study population can be found in Tables 4.1.1 and 4.2.1.

Table 4.1.1 Characteristics of the respondents subdivided according to their level of education

Characteristics	Low-educated ^a respondents (n=6)	Moderately educated ^b respondents (n=13)	Highly educated ^c respondents (n=5)
Mean age (range) Years	65.8 (47-97)	50.5 (18-73)	56 (32-76)
Male	2	5	2
Female	4	8	3

^aLow=no education or primary education.

^bModerately=lower secondary education, (upper) secondary education, or postsecondary non-tertiary education (including vocational education).

^cHighly=tertiary education (bachelor's degree or higher).

Table 4.1.2 Characteristics per respondent

Pseudonym	Age (years)	Educational level ^a	Last occupation
Jerome	47	Low	Truck driver
Michelle	56	Low	Cleaning lady
Ida	66	Low	Cleaning lady
Ronald	70	Low	Home painter
Dora	77	Low	Cleaning lady
Ilene	79	Low	Cleaning lady
Peter	18	Moderate	Student
Jude	18	Moderate	Student
Joline	19	Moderate	Photographer
Sandra	39	Moderate	Graphic designer
Christine	39	Moderate	Nurse for mentally disabled people
Lydia	56	Moderate	Domiciliary care
Rose	60	Moderate	Saleswoman
Francine	61	Moderate	Administrative officer
Henry	64	Moderate	Project coordinator
Bob	68	Moderate	Cashier
Roger	70	Moderate	Home painter
Bill	72	Moderate	Order picker
Mia	73	Moderate	Administrative officer
Ellen	32	High	Management assistant
Helga	54	High	Artist
Jill	55	High	Management assistant

table continues

Pseudonym	Age (years)	Educational level^a	Last occupation
Harald	63	High	Financial controller
Bernie	76	High	Lecturer chemistry

^aLow=no education or primary education; moderate=lower secondary education, (upper) secondary education, or postsecondary non-tertiary education (including vocational education); and high=tertiary education (bachelor's degree or higher).

Data Collection and Procedures

Data collection took place at the respondents' homes or at the physical therapy practice of the respondent's physical therapist. The choice of location depended on the preference of the respondent. Two researchers were present (researchers IT and JS). Researcher IT conducted the interviews. When researcher JS missed information, she asked complementary questions.

The TSTI method was conducted as follows [21]:

Step 1: researchers IT and JS observed each respondent as they completed the DTTSQ while thinking out loud. This step was aimed at collecting observational data regarding the respondent's response behavior. The data collected consists of two types: (1) observations of respondent's behavior and (2) think-aloud data. The data were recorded in the form of videotapes as well as audiotapes for later analysis and real-time notes by the researchers for use during the interview itself and later analysis. The researchers wrote their notes down on hardcopies of print screens of the DTTSQ.

Step 2: after the respondent finished completing the DTTSQ, researcher IT conducted an in-depth interview to clarify and complete the observational data. During this step, researcher IT only focused on those actions or thoughts she felt not fully informed about or were not fully clear to her. This step was aimed at filling gaps in the observational data and check information.

Step 3: during the final step, researcher IT conducted a semi-structured interview aimed at eliciting experiences and opinions of the respondent. In this part of the interview, the respondent was stimulated to add secondary data such as accounts and reports of feelings, explanations, preferences, recommendations, etc. Researcher IT asked the respondent to paraphrase questions and to explain in his

own words how he interpreted the question and why he chose the answer options he chose. When a respondent encountered problems in responding to a question, he was asked what he thought the exact nature of the problem was and why he behaved as he did in response to the question. He also was asked for suggestions for improvement of the question in terms of wording, layout, instructions, etc. Additionally, the respondent was asked to describe his health problem(s) and treatment goal(s) in his own words. Comparing these descriptions to the respondent's responses to the questionnaire during step 1 of the TSTI provided useful information as indicators of the validity of the data collected by the DTTSQ. Finally, the respondent was asked if he recognized himself in the outcomes of the questionnaire that were shown at the end of the questionnaire (see Appendix 1: 15. "Overview all outcomes of the questionnaire"). After the TSTI was finished, researcher IT collected the demographic data through a brief structured interview.

Data Analysis

Data were analyzed using a thematic content analysis approach [27]. Four types of data were analyzed: (1) video recordings of the first two steps of the interview, (2) Dutch transcriptions of the third step of the interview, (3) observed respondent behavior in field notes, and (4) background information regarding the educational level, age, gender, and occupation of each respondent. Researcher MW started with open coding, coding all fragments of the twenty-four transcripts of step three of each interview using MAXQDA 10 of VERBI Software GmbH, Berlin. The codes and fragments of seven randomly selected transcripts were validated by two peer researchers by independently coding each transcript with the coding scheme developed by researcher MW. Differences in fragmentation or coding were discussed during consensus meetings.

To get more familiar with the data and to create an overview, researcher MW made a descriptive summary of each case on the basis of all four types of generated data after she finished open coding. Each summary contained all emerging themes regarding problems that occurred during the four phases of the response process as described by Tourangeau: (1) *comprehension*: (a) comprehension of text and wording and (b) interpretation of the meaning of the text, (2) *retrieval*: gathering relevant information, (3) *judgment*: assessing the

retrieved information to judge its adequacy in relation to the meaning of the question, and (4) *response selection*: selecting the best fitting answer option [28]. The emerged themes in the summaries were supplemented with related field notes and background information regarding the educational level, age, gender, and occupation of the respondent. Then researcher MW listed all emerging "themes" from the descriptive summaries regarding problems that arose during the four steps of the response process. She established which themes recurred or were common and which were less common or stood alone.

Then she structured the earlier created coding scheme by arranging all open codes by labeling them as, 'problem with comprehension,' 'problem with interpretation,' 'problem with retrieval,' 'problem with judgment,' or 'problem with response selection.'

The following step in analyzing the data was comparing the description of the limitations in functioning and treatment goals described by respondents during the semi-structured interview (interview step 3) to the answer options the respondent selected in the DTTSQ during the think-aloud phase of the data collection (interview step 1). If the chosen answer during step 1 did not fit the description in step 3, researcher MW closely watched the video again to see which actions or thoughts during the four steps of Tourangeau [28] during the response process of the question led the respondent to select the chosen answer option.

As a last step, researcher MW compared the analyzed interviews of low, moderately, and highly educated respondents to see whether or not the problems that occurred during the response processes differed between these groups of respondents.

Transcripts were made in Dutch language. Only quotes used in this paper were translated from Dutch to English by researcher MW and checked by researcher HW, who is a bilingual speaker.

During the whole course of the study, procedures and results were checked and discussed with researchers HW, MJW, and WD.

Ethics

No external funding was received by the Utrecht University of Applied Sciences to conduct this study. The study was registered with the Medical Ethics Commity of the Academic Medical Centre of Amsterdam, which declared that it does not fall under the scope of the "Medical Research Involving Human Subjects Act." The study was conducted according to the principles of the Declaration of Helsinki. All respondents provided written informed consent. The respondents names used in this paper are all fictitious to protect their privacy.

RESULTS

Encountered Problems

Of the 24 respondents, 20 encountered one or more problems during their response process. Low-educated Michelle and moderately educated Christine, Lydia, and Sandra did not encounter any problem. All members of the total study population stated that they recognized themselves in the overall outcomes of the questionnaire. Bernie stated the following:

"If I would have developed this questionnaire so it would have fitted my health problem I would have done it differently. Instead of selecting specific points on the body chart, for instance, I would have enabled people to select regions. In my case that would have enabled me to select the whole lower part of my body instead of a few specific points in it. But even though I would have done it differently, I recognize myself in the summary of my limitations in functioning. That is mainly due to the pictures of the activities in which I am impaired. When I look at all the outcomes as a whole, it is right. I recognize my own health situation."

Most problems concerned interpretation of questions and answer options. Questions 1 and 4 generated the most problems. Question 3 generated no problems at all (see Table 4.1.3).

Table 4.1.3 Number of respondents having problems per question for each step of the response process

Question or assignment	Comprehension problems	Interpretation problems	Retrieval problems	Judgment problems	Response selection problems
1. Do you have pain? (Appendix 1: 2. "Pain")	-	6	-	-	-
2. Tap on the location of your health problem. You can tap on multiple locations. (Appendix 1: 3. "Location of the health problem")	-	-	1	1	2
3. This is the location of your pain. Rate the severity of your pain on the scale below. (Appendix 1: 4. "Pain severity")	-	-	-	-	-
4. Select the activities in which you are impaired. (Appendix 1: 7. "Activity "Lying"")	-	9	6	8	3
5. Select the three activities which are most important to you. (Appendix 1: 9. "most important activities")	-	-	-	-	2
6. Select the activity which is most important to you. (Appendix 1: 11. "Most important activity 1")	-	1	-	-	-
7. Which of these two activities is most important to you now? (Appendix 1: 12. "Most important activity 2")	-	1	-	-	-
8. Rate the effort it takes to carry out this activity. (Appendix 1: 13. "Effort activity 1")	-	2	-	-	2

Problems With Comprehension of Text and Wording

There were no problems with comprehension of text and wording.

Problems With Interpretation

A total of 13 respondents of all educational groups encountered problems with interpretation. Ronald and Bob encountered this problem with three questions and Helga and Jerome with two different questions. The other 9 respondents encountered this problem with one question.

Interpreting Pictures

A total of 7 respondents interpreted pictures that were used as answer options in question 4 differently than was intended by the developers of the questionnaire.

Ilene, for instance, selected 'dressing and undressing' (Figure 4.1.1) and going to the toilet (Figure 4.1.2) because the way in which the person in the picture carried out the activity and the context in which he did it were different from theirs. This is illustrated in the following quotes:

Ilene:

"I selected 'dressing and undressing' because the person on the photo is standing up while he is dressing himself. I cannot do that. I have to sit down."

Interviewer:

"Would you have selected this activity if the person on the photo was sitting down while he dressed and undressed himself?"

Ilene:

"No, because that is no problem for me. That is the way I do it. It is the same with going to the toilet. I selected that photo because the person on the photo does not use the support arms while he is using the toilet."

Interviewer:

"Would you have selected the photo if he would have used the support arms?"

Ilene:

"No of course not! I do not have any problem going to the toilet because I have these support arms. I have everything I need in my house."



Figure 4.1.1



Figure 4.1.2

Interpreting Categories

The answer options in the form of pictures of question 4 were put into eight different activity categories. These categories were shown on eight separate screens. The use of categories influenced the response process of two respondents negatively. Rose, for instance, recognized her impairment in the activity "reaching for something above the head," but did not select it, as illustrated in the following quote:

"I really was in great doubt with 'reaching!' Because I thought: yes indeed that is problematic for my shoulder so I should select that activity. But the activity was placed in the category 'standing' which I associated with using the legs and back, not with arm movements. In hindsight I probably should have selected it, but when I was completing the questionnaire I chose not to."

Interpreting Plain Language

Six respondents misinterpreted question 2 "Do you have pain?" Four of them mentioned the short and simple way in which the question was formulated as the reason for this misinterpretation. All six respondents selected the answer "no," whereas in fact they were seeking help with their physical therapist because of pain complaints. Henry stated the following:

"Well I am not in pain at this moment. But when I go photographing I take long walks carrying heavy lenses. And then my hip hurts sometimes. This is something my physical therapist needs to know because it should be the aim of the treatment. But I interpreted the question as 'are you in pain at this moment.' And that is why I answered 'no.' The sentence, the question, is very short. It is not specific enough. It should have said: 'Are you in pain during certain activities' or something."

Differences in Professional and Layman Interpretations

Although 'getting up and sitting down' and 'getting in and out of a car' are different activities from a physical therapist's perspective, these are very similar movements from the perspective of moderately educated Bob, who stated the following:

"Well 'getting up and sitting down' and 'getting in and out of a car' are kind of the same activities to me. So it is hard for me to say

which one is more important in answer to question 6 and 7. I know I selected 'getting in and out of the car' as the most important activity when I was completing the questionnaire. But when I would have to choose again I would go with 'getting up and sitting down,' because that is more generic and therefore it occurs more frequently in daily life."

4.1

Interpreting the Numeric Rating Scale

Low-educated Dora and Ronald scored the numeric rating scale of question 8 backwards. They interpreted 10 as 'no effort' and 0 as 'the most effort possible'.

Problems With Retrieval

A total of 7 respondents of all educational groups had problems retrieving information during their response processes.

Lack of Retrieval Because of the Form of Answer Options

A total of 4 respondents did not retrieve information because of the lack of answer options. They looked at the body chart of question 2 and the pictures of question 4 and searched their memory for any health problems related to the answer options. As a result, existing health problems that were *not* associated with the given answer options were *not* retrieved from memory. After Harald finished completing the questionnaire, he told the researcher that he was impaired in pulling objects, which is not a given answer option in question 4. Harald stated the following:

"I did not miss it while I was completing the questionnaire. I probably thought that that picture would come later or in another category or something. I don't know. I did not really notice that it wasn't there."

Lack of Retrieval Because of Memory Issues

In three cases, the root of the problem seemed to be a memory issue, which was not related to the content or form of the questionnaire. Ellen, for instance, described to the interviewer why she selected the activities "lifting" and "carrying" in answer to question 4. During this description, her recollection of the health problem became clearer. This made her realize in hindsight that "picking something up from the floor" would have been a better answer.

Problems With Judgment

A total of 9 respondents of all educational levels encountered problems with judgment.

Retrieved Information Judged as 'Adequate to Answer the Question' Was Not Related to Physical Therapy (Anymore)

All 9 respondents indicated health problems that were not part of their treatment goal for physical therapy (anymore). Bob, for instance, indicated on the body chart that he had pain in his neck and shoulders, *and* he had low back pain. During the interview, he told the researcher that his neck and shoulder pain were chronic and existed for many years now. He did not believe it would be of any use for the physical therapist to put effort into trying to ease this pain. Therefore, it was not a part of his treatment goals. He was seeking help from his physical therapist for his acute low back pain.

Problems With Response Selection

A total of 8 respondents of all educational levels had problems with response selection. Bernie encountered this problem with two different questions of the questionnaire.

Not Able to Select the Right Answering Option Because These Options Do Not Match the Respondent's Response to the Question

All 8 respondents had problems with response selection because the response items did not match their answer(s). Bernie for instance had a complaint that was not 'touchable' or located at a particular part of the body. But he was forced to place a dot on the body chart to be able to go on to the next question. Bernie stated the following:

"This is not right at all! It says: 'tap on the location of your health problem.' But then one has to be able to locate his complaints. I can't. The way I walk does not feel normal to me, it does not feel the way it used to feel. I cannot say that I feel it 'in my legs.' It really is the movement itself that feels 'off.' I go to the physical therapist to find out what causes this. So at this moment I don't know where the root of the problem is located. Because I am forced to point out a location and the legs are clearly involved in walking, I have put a dot on the legs. But it is just not right. I mean, when I would have had pain in my hand I could have answered this question. If I would have felt it in my foot I would have tapped on the foot. But in my case it is about the movement..."

DISCUSSION

Principal Findings

Of the 24 respondents, 20 encountered one or more problems during their response process. No problems were experienced with comprehension of text or wording. Most problems arose with (1) Interpretation of pictures and plain language, (2) Respondents not retrieving health problems that were *not* associated with the given answer options, and (3) Respondents judging retrieved health problems as relevant, although these were not related to their physical therapy treatment goals. No educational group in this research population stood out from the rest in the kind or number of problems that arose.

Despite the fact that 20 respondents did not respond to each question in the way that was intended by its developers, all respondents recognized themselves in the outcomes of the questionnaire shown in a screen summary.

Comparison With Prior Work

The clarity of text and wording seems to be better in the DTTSQ than in the PSC questionnaire [17], which was used as a starting point for development. In the study on the response process of the PSC questionnaire, "comprehension" and "interpretation" were put together into one category called "problems with reading and comprehending the questionnaire" [19]. Due to the way in which the data was collected in the PSC questionnaire study (lacking a think-aloud component), even in hindsight it is not always possible to determine if the source of each "problem with reading and comprehending the questionnaire" was comprehension or interpretation. This makes the PSC questionnaire and DTTSQ studies not fully comparable in this respect. Still, little over half of the respondents in the DTTSQ study versus all respondents in the PSC questionnaire study had comprehension and/or interpretation problems.

Invalid answers were reported in 52% (13/25) of the Dutch subjects in the PSC questionnaire study [19]. In this study, the percentage of respondents that gave one or more invalid answers was much higher: 83% (20/24) cases. Again the data of these two studies are not fully comparable. The PSC questionnaire study did not contain a think-aloud component. Having a think-aloud component in a study tends to add

data on validity of answers, while at the same time there is no loss of data in comparison to studies without a think-aloud component [21]. This may be an explanation for the considerable difference between the amount of invalid answers found between the two studies.

Except for the problems caused by the use of plain language, using pictures as answer options and showing questions on separate screens without a back function, the problems found in this study were not new or exclusive for the DTTSQ. Problems such as "differences in layman and professional perspective" and "memory issues" are commonly seen in comparable studies and well documented in Tourangeau's book "The psychology of Survey Response" [23,24,26,28].

Problems Caused by the Use of Plain Language

Four out of 6 respondents that misinterpreted question 1 of the DTTSQ "Do you have pain" mentioned the short and simple formulation of this question as the root of the problem. The formulation of question 1 and the layout of the screen on which it was shown was in line with the "European Easy-to-Read Guidelines" [29]. With the formulation of this question, however, the developers of the questionnaire may not have done enough justice to the complex concept of pain. It may be necessary to provide more detailed background information on the purpose and focus of the question [30]. Considering that understanding *spoken* language is easier to people than understanding *written* language [31], it might be recommended to add information by using a voice-over. In this way, information on the purpose and focus of the question and/or answer option(s) can be given without making the reading task more difficult [32].

Problems Caused by the Design of the User Interface

1. Use of Pictures

In addition to plain language, pictures were used to contribute to the comprehensibility of the questionnaire. Respondents' interpretation of the pictures did not always match the intended meaning by its developer. Optimizing this match by testing the interpretation of newly developed pictures in the target population before they are used in the questionnaire is recommended during the further development of the DTTSQ.

2. Showing All Questions on Separate Screens

The questions of the DTTSQ were shown in separate screens, and respondents were not able to go back to earlier screens. This makes the response process different from that of paper-based questionnaires in which respondents are able to oversee the whole questionnaire, choose the order in which they answer questions, and go back and forth between questions. The answer options of question 4 were subdivided into eight categories shown on eight separate screens. Lacking the complete overview of all answer options may have complicated the decision on whether or not to select an activity because the respondent was not able to see whether or not pictures in coming screens would be a better fit. Giving a complete overview of all answer options, for instance by presenting them as thumbnail images [33] and providing a back option, may help to reduce the amount of problems with response selection.

Limitations

This study was not designed to reach data saturation. The goal was to get a first impression of the response processes of respondents with diverse educational levels completing the prototype of the questionnaire to be able to make informed choices in further development of the questionnaire. Because twenty-four cases were included in this study, it can be assumed that the most common problems have been exposed [34].

Conclusions

The use of plain language and ICT within the DTTSQ has had positive and negative influences on the response processes of the research population.

Results of recent reviews and articles on the comparability of paper-based and electronic versions of questionnaires may give the impression that digitalizing questionnaires can be done without influencing psychometric properties [35-39] and response rates [40-44]. This is true when the digital version is a near copy of the paper-based questionnaire in terms of content and layout. But in an era in which the use of plain language and "inclusive design" or "electronic health for all" [45,46] is being advocated increasingly [47,48], copying the content and layout of the original into the digital version may not be enough.

The results of this study emphasize the importance of two basic recommendations:

1. Accompany any adaption of any questionnaire to a new mode of delivery by evidence, demonstrating the difference and equivalence between the two different modes [49].
2. Scientifically evaluate the applicability of the newly developed mode of the questionnaire in its intended setting, to assess if it meets the standard criteria of validity, reproducibility, and feasibility [50]. Such studies should be designed and executed in a way that suits the (in)abilities of the target population of the questionnaire that is being evaluated. Like the qualitative method chosen in this study suited the (in)abilities of low-educated and/or low-literate participants by not demanding any reading or writing skills from study participants.

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Conflicts of Interest

None declared.

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Abbreviations

DTTSQ: Dutch Talking Touch Screen Questionnaire

HCP: health care provider

ICT: information and communication technology

PSC: Patient Specific-Complaint

TSTI: Three-Step Test-Interview

4.2

A Mobile Patient Reported Outcome Measure (PROM) App for Physical Therapy Patients: Usability Assessment of the Dutch Talking Touch Screen Questionnaire

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ABSTRACT

Background

In the past years a mHealth app, called the Dutch Talking Touch Screen Questionnaire (DTTSQ) was developed in The Netherlands. The aim of development was to enable Dutch physical therapy patients to autonomously complete a health related questionnaire regardless of their level of literacy and digital skills.

Objective

The aim of the current study was to evaluate the usability (defined as the effectiveness, efficiency and satisfaction) of the prototype of the DTTSQ for Dutch physical therapy patients with diverse levels of experience in using mobile technology.

Methods

The qualitative Three-Step Test-Interview method, including both think-aloud and retrospective probing techniques, was carried out to get insight into the usability of the DTTSQ. Twenty-four physical therapy patients were included. The interview data were analyzed using a thematic content analysis approach aimed at analyzing the accuracy and completeness with which participants completed the questionnaire (effectiveness), the time it took the participants to complete the questionnaire (efficiency) and the extent to which the participants were satisfied with the ease of use of the questionnaire (satisfaction). The problems encountered by the participants in this study were given a severity rating which was used to provide a rough estimate of the need for additional usability efforts.

Results

All participants within this study were very satisfied with the ease of use of the DTTSQ. Nine participants stated that the usability of the application exceeded their expectations. The group of four average/high experienced participants encountered only one problem in total, while the eleven little experienced participants encountered an average of 2 problems per person and the nine non-experienced participants an average of 3 problems per person. Thirteen different kind of problems were found during this study. Four of these problems need to be addressed before the DTTSQ will be released because they have the potential to negatively influence future usage of the tool. The

other nine problems were less likely to influence future usage of the tool substantially.

Conclusions

The usability of the DTTSQ needs to be improved before it can be released. No problems were found with satisfaction or efficiency during the usability-test. The effectiveness needs to be improved by 1. making it easier to navigate through screens without the possibility of accidentally skipping one, 2. enable the possibility to insert an answer by tapping on the text underneath a photograph instead of just touching the photograph itself and 3. making it easier to correct wrong answers. This study shows the importance of including less skilled participants in a usability study when striving for inclusive design and the importance of measuring not just satisfaction but also efficiency and effectiveness during such studies. Further research is necessary to gain more insight into the needs, preferences, capacities, values, and goals in relation to mHealth technology of people with little or no experience with using mobile technology.

4.2

INTRODUCTION

EHealth is developing rapidly [1]. It is defined as the use of information and communication technology (ICT) in healthcare [2]. A growing amount of literature indicates that using eHealth can improve the accessibility, quality and efficiency of health care [3,4,5]. It seems to be effective for people who have access to it and are able to use it well, which is not the case for everybody [6,7]. For instance, people with low income or low education and people who are 65 years and older are vulnerable when it comes to effective eHealth use. In these populations access to the internet and hardware like personal computers, tablets, mobile phones and smartphones and experience and skills to use these devices is low [6,7,8,9]. Differences between people regarding digital skills and access to internet and hardware is often referred to as the digital divide [10,11]. Since eHealth technologies are usually primarily developed for people who are experienced and skilled in using ICT [12,13], people who do not have access to ICT or are not skilled in using it, are at risk of being excluded from the use of eHealth. Looking at the widespread expansion of eHealth technologies this encompasses the potential threat of contributing to the ongoing exacerbation of health inequalities in western countries [1]. However, if the needs,

preferences, capacities, values, and goals of potential future users who do not have good access to internet and digital technology or who are not well skilled in using this technology, would be explored and taken into account during each stage of development of eHealth tools, eHealth could potentially *reduce* health inequalities [14].

The development of a specific form of eHealth technology, called mobile health (mHealth) technology, seems especially promising when it comes to reducing health inequalities [15,5,16,17]. MHealth has been defined by the Global Observatory for eHealth of the World Health Organization as "medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants, and other wireless devices" [18]. A recent project called eSalud showed that mHealth can be cost effective, help to overcome cultural and language barriers and provide health information and services to low health access areas [15]. Furthermore, recent publications indicate that the digital divide is narrowing because of the increased ownership of mobile devices such as smartphones and tablets [5,16,17].

Still, having access to internet and digital technology does not automatically mean that people are able and willing to use it effectively to increase their health nor that different people use it in the same way [14, 19, 20,21,22,23,24,25]. Recent studies found ethnic and socioeconomic differences in mHealth usage [19,20] and it is known that older people use mHealth differently from younger people [14]. And though the gap of people owning tablets and smartphones between groups is closing, still a substantial amount of people do not own such devices. For instance the percentage of Dutch citizens of 65 years and older owning a tablet computer in 2017 was 55.2% versus 75.8% citizens of 12-25 years of age [26]. Considering that vulnerable groups, like people with low income and low education, bear a disproportionate burden of disease [27,28] and the amount of healthcare visits increases with age [29] it is to be expected that a relatively large amount of care recipients do not have a lot of experience using mobile technology. To fulfill the promise of mHealth technology contributing to reduction of health inequalities, it is very important to carefully test the usability of mHealth applications in research populations which include members of the target populations that are at risk of being excluded from usage of the tested tool.

In the past years a prototype of a mHealth application, called the Dutch Talking Touch Screen Questionnaire (DTTSQ), was developed in The Netherlands. The idea of developing a talking touchscreen was inspired on the work of Hahn and Cella [30]. The aim of developing the DTTSQ was to enable Dutch physical therapy patients to autonomously complete a user-friendly health related questionnaire regardless of their literacy and digital skills. Because it is not to be expected that all physical therapy patients own a tablet computer, the DTTSQ is meant to be presented in a physical therapy practice on a tablet computer that is owned by the physical therapy practice concerned. Patients are asked to complete the DTTSQ in the waiting room of the physical therapist prior to their first visit. The development of the prototype of the DTTSQ, which runs on a tablet computer, was described in detail by Cremers et al. in 2015 [31]. Prior to the current study the prototype was only tested in a sample *outside* of the physical therapy context.

The aim of this study was to test the prototype of the DTTSQ within the physical therapy context to see what parts of the prototype needed adjustment in order for it to be user-friendly for physical therapy patients regardless of their level of experience with operating mobile technology.

The research question underlying this study was: What is the usability of the prototype of the DTTSQ for physical therapy patients with different levels of experience in using mobile technology?

METHODS

Design

A qualitative descriptive study was carried out. Observational data on the way participants operated the DTTSQ was collected through The Three-Step Test-Interview (TSTI) method [32]. This method includes both think-aloud and retrospective probing techniques.

Definitions

Usability was defined by the International Standards Organization (ISO) as "the effectiveness, efficiency and satisfaction with which specified users can achieve goals in particular environments" [33]. *Effectiveness* is the accuracy and completeness with which users achieve certain goals [34]. In this study problem rates and severity

of problems were used as the primary indicator of effectiveness. *Efficiency* is the relation between the accuracy and completeness with which users achieve certain goals and the resources expended in achieving them [34]. In this study completion time was used as an indicator of efficiency. *Satisfaction* is the users' comfort with and positive attitudes towards the use of a system [34]. In this study participants were interviewed about their satisfaction with the ease of use of the DTTSQ. Ease of use was defined as the degree to which the usage of a particular system is free from effort [35].

Setting and Participant Selection

Data was collected in the same study population and at the same time as the data reported in a paper earlier published by Welbie et al. [36]: Recruitment took place in eleven primary care practices in deprived areas of Utrecht, The Netherlands. Patients were invited by their physical therapists to participate in this study. The physical therapists shortly explained the goal of the study and provided the patient with an information letter that was written in plain Dutch language. If patients were interested, the physical therapist asked permission to give the patients' telephone number to researcher IT. Then researcher IT (1) contacted the patient by telephone, (2) again shortly explained the aim of the study, (3) made sure the patient understood what was asked of him/her, (4) answered any question the potential participant may have had, and (5) checked the inclusion criteria. Inclusion criteria for participants were as follows: aged 18 years or older, Dutch as their first language, and the patients and both their parents born in The Netherlands. This last inclusion criterion was added, because in a following study the usability of a direct Turkish translation of the DTTSQ will be tested. In order for the outcomes of both studies to be comparable it is important that the cultural background of participants of the current study was not 'mixed'. This last inclusion criterion excludes second generation immigrants with a non-Dutch background. The sampling procedure was aimed at getting a broad variation in levels of education and age, plus balance in our sample regarding gender. Age was used as a proxy for level of experience with using mobile technology, because with increase of age the experience with mobile devices decreases [26]. Taking age as a selection criterion was more practical for the recruiting physical therapists, as this is noted standardly in patient files. By making sure that there was variation in age it was expected to find variation in

experience with mobile devices in the study sample. Throughout the recruitment process, the recruiting physical therapists were constantly kept informed about the profiles of participants the researchers were looking for. In total, 24 physical therapy patients were included in this study [36]. Characteristics of the study population can be found in tables 4.2.1 and 4.2.2.

Table 4.2.1 Characteristics of study population

Characteristics	Study population (N=24)
Mean age (range) years	56 (18-79)
Gender, n (% of N)	
Male	9 (38)
Female	15 (62)
Level of education, n (% of N)	
Low ^a	6 (25)
Moderate ^b	13 (54)
High ^c	5 (21)
Self-declared experience with using mobile technology, n (% of N)	
None	9 (37)
Little	11 (46)
Average/high	4 (17)

^a Low = no or at most primary education finished

^b Moderate = lower secondary education, (upper) secondary education or post-secondary non-tertiary education (including vocational education)

^c High = Tertiary education (bachelor's degree or higher)

Table 4.2.2 Characteristics per participant

Pseudonym	Experience mobile technology	Age	Level of education
Ida	None	66	low ^a
Bill	None	72	moderate ^b
Mia	None	73	moderate ^b
Dora	None	77	low ^a
Ilene	None	79	low ^a
Bob	None	68	moderate ^b
Jerome	None	47	low ^a
Helga	None	54	high ^c
Michelle	None	56	low ^a
Roger	Little	70	moderate ^b
Peter	Little	18	moderate ^b

table continues

Pseudonym	Experience mobile technology	Age	Level of education
Christine	Little	39	moderate ^b
Jill	Little	55	high ^c
Lydia	Little	56	moderate ^b
Rose	Little	60	moderate ^b
Francine	Little	61	moderate ^b
Harald	Little	63	high ^c
Henry	Little	64	moderate ^b
Ronald	Little	70	low ^a
Bernie	Little	76	high ^c
Jude	average/high	18	moderate ^b
Joline	average/high	19	moderate ^b
Ellen	average/high	32	high ^c
Sandra	average/high	39	moderate ^b

^aLow = no or at most primary education finished

^b Moderate = lower secondary education, (upper) secondary education or post-secondary non-tertiary education (including vocational education)

^c High = Tertiary education (bachelor's degree or higher)

Content of the Dutch Talking Touch Screen Questionnaire

The prototype of the Dutch Talking Touch Screen Questionnaire was a digital application on a tablet computer. It was developed during a co-design process [37] which in this case meant that a group of ten low literate people helped to design the questionnaire. As a result of the co-design process, questions on pain location and pain intensity were added to the original questions of an existing questionnaire which aims to select limitations in functioning and to formulate specific treatment goal(s) [38,39]. Furthermore, visual (videos and photo's) and auditory (speech technology) support were added to enable participants to see and hear the questions which were shown on separate screens. Response items could be selected by tapping on the touch screen and plain language was used in all spoken and written text within the Dutch Talking Touch Screen Questionnaire [31]. An overview of all types of screens is given in Appendix 1. The eight questions of the questionnaire can be found in screenshots 2, 3, 4, 7,9,11,12 and 13 which can be found in Appendix 1.

Instructions

Instructions were given in the form of three video clips:

1. an introduction clip in which the purpose of the questionnaire and all functions of the questionnaire were explained (see Appendix 1, screenshot 1).
2. an instruction clip in which the purpose of question 4 and a newly added navigation function were explained (Appendix 1, screenshot 6).
3. a closing clip in which the participant is thanked, explained what the physical therapist would do next and told that the questionnaire would close down automatically (Appendix 1, screenshot 16).

Functions

Next button:

Navigation function to go to the next screen. Not activated unless a response item is selected (except for question 4 (see Appendix 1, screenshot 7)).

Help button:

Activates the help function: the text on the screen is read aloud, the purpose of the question is explained and operating instructions for the particular screen are provided.

Correction function:

Tapping a second time on a response item de-selects the item.

Stop button:

Escape function: shuts down the questionnaire. All previous given answers are saved.

Overviews

To help participants keep track of their answers, overviews of previous given answers were provided regularly during completion of the questionnaire (see Appendix 1, screenshots 5,8,10,14 and 15).

Data collection and procedures

Data collection took place at the physical therapy practice or the participant's home, depending on the preference of the participant. Researchers IT and JS were present. Researcher IT was in the lead during the interviews. Researcher JS asked complementary questions if she missed information.

The following steps were taken according to the TSTI method [32]:

Step 1

Each participant was observed by researchers IT and JS while they

were completing the DTTSQ thinking out loud. This step was aimed at collecting observational data regarding the usability of the DTTSQ. The data collected consisted of two kinds: 1. observations of participant's behavior and 2. think-aloud data. The data was recorded on videotapes as well as audiotapes. Additionally, the researchers took real time notes for use during the following steps of the interviews as well as for later analysis. The researchers wrote their notes down on hardcopies of print screens of the Dutch Talking Touch Screen Questionnaire. Researchers IT and JS noted problems with operating the tablet computer including using the touchscreen, navigating through the questionnaire, understanding the task given in each screen, selecting response items and using the correction function. They also wrote down when the stop button was used. The researchers did not interfere in the completion process by asking any questions or providing help.

Step 2

Researcher IT conducted an in-depth interview after the participant finished completing the DTTSQ. Data collection during this step was exclusively focused on filling possible gaps and checking the observational data collected during step 1.

Step 3

During step 3 of the TSTI researcher IT conducted a semi-structured interview aimed at eliciting experiences and opinions of the participant. During the interview each screen was operated in the same way the participant did during step 1 and the same answers were entered. This was done to help the participant to clearly remember all his thoughts and actions during the completion of the questionnaire. Participants were stimulated to report feelings, express opinions, preferences and recommendations. If they encountered problems in operating the DTTSQ they were asked what they thought the exact nature and possible cause of each type of problem was and how they tried to overcome the problem. Then the participants were questioned about their satisfaction regarding the ease of use of the user interface, technical operation, layout and content and overall usability of the DTTSQ. Researcher JS was allowed to ask complementary questions, if she felt it was necessary, in order to get complete and enriched data. Researcher IT finished the interview by collecting demographic data and data on self-reported experience with mobile technology (see table 4.2.1 and 4.2.2).

Analyses

Data were analyzed using a thematic content analysis approach [40]. Four types of data were analyzed: 1. Video recordings of the completion of the questionnaire, 2. field notes of the observed participant behavior 3. transcriptions of the audio recordings of the semi-structured interviews and 4. background information regarding the educational level, age, gender, and self-reported experience with using mobile technology.

To get more familiar with the data and to create an overview, researcher MW made a descriptive summary of each case on the basis of all four types of generated data. Each summary contained information on whether or not the questionnaire was fully completed, if, when and why the stop function was used, the kind of problems that occurred with the operation, the completion time and all emerging themes regarding satisfaction or dissatisfaction with the ease of use of the questionnaire. The summaries were supplemented with information regarding educational level, age, gender and experience in using mobile technology.

Subsequently, researcher MW derived the observed problems from the summaries. She clustered the problems. For every new problem a new category was made. MW analyzed the video recordings to see how many times each problem was made in total, per participant and per question/screen of the questionnaire. After a full overview of problems had emerged she scored the level of severity of each problem as described by Nielsen and Loranger [41]: low, medium, serious or critical. To score severity she used the method of Hattink et al. [42]: The severity was scored by answering the three questions of Nielsen and Loranger [41] with 'yes' (= one point) or 'no' (= 0 points):

1. *Frequency*: Does a substantial amount of users encounter the problem? Within the current study this question was answered with 'yes' if one third or more participants had encountered the problem.
2. *Impact*: Does the problem cause much trouble to those users who encounter it? Within the current study this question was answered with 'yes' if the problem had led at least one participant to stop completing the questionnaire.
3. *Persistence*: Does the problem cause trouble repeatedly? Within the current study this question was answered with 'yes' if the

problem had occurred with an average of more than one time per participant.

This resulted in a 0-3 point score per problem. Each score was related to a level of severity: 0 = low, 1 = medium, 2 = serious and 3 = critical. These severity-ratings give an indication of which problems lead to disastrous usability problems and which problems are more cosmetic in nature [43]. This provides insight into whether or not the usability of the DTTSQ needs to be improved before it can be released. Nielsen and Loranger recommend to tackle only serious and critical severe problems during the development process of a digital tool. Low and medium severe problems do not have priority according to Nielsen and Loranger, because although they are bothersome, they are not likely to directly influence the usage of a tool. This makes it uninteresting to tackle them from a cost-benefit perspective. Serious and critical severe problems on the other hand can be so disrupting that they can make users stop using a tool or prevent them from even starting to use it at all. Therefore, they should not be ignored during the development process of a digital tool [41].

As a next step researcher MW started open coding of all fragments in the transcripts of the semi-structured interviews that were related to (dis)satisfaction about the ease of use of the questionnaire using Maxqda 10 of VERBI Software GmbH, Berlin. After she finished open coding she organized and structured the codes until a coding scheme emerged on the basis of which the part of the research question that was related to satisfaction of the participants could be answered sufficiently.

As a last step researcher MW ordered the analyzed data into three groups: data of participants who had (1) no, (2) little and (3) average/high experience in using mobile technology. This was done to see whether or not data differed within and between these groups.

During the whole course of the study procedures, coding, analysis steps and interpretation decisions were discussed with researchers HW, MJW and WD.

Ethics

No external funding was received by the Utrecht University of Applied Sciences to conduct this study. This study was submitted to

the Medical Ethics Committee of the Academic Medical Centre of Amsterdam which declared that it does not fall under the scope of the 'Medical Research Involving Human Subjects Act'. The study was conducted according to the principles of the Declaration of Helsinki. All participants provided written informed consent. The participants' names used in this article are all fictitious in order to protect their privacy.

RESULTS

4.2

Effectiveness

Nine out of the twenty-four participants in this study did not complete the DTTSQ fully (see table 4.2.3). Michelle (56yrs), Bill (72yrs) and Helga (54yrs), who were all inexperienced in using mobile technology stopped completing the questionnaire by using the stop button. Inexperienced Ida (66yrs), Ilene (79yrs), Dora (77yrs) and Mia (73yrs) and little experienced Peter (18yrs) and Rose (60yrs) went through the whole questionnaire but unintentionally left one or more parts open.

Table 4.2.3 Experience with mobile technology and completion of the DTTSQ

(sub)population	not fully completed	fully completed
No experience using mobile technology (n=9)	7	2
Little experience using mobile technology (n=11)	2	9
Average/high experience using mobile technology (n=4)	-	4
Total population (N=24)	9	15

Unanswered (parts of) questions

Inexperienced Michelle (56yrs), Ida (66yrs), Ilene (79yrs), Dora (77yrs), Mia (73yrs) and little experienced Peter (18yrs) and Rose (60yrs) failed to fully complete the DTTSQ because they failed to select answer options and/or unintentionally skipped questions by double-tapping on the next button (see problem 1-5 in table 4.2.4). All participants, except for Michelle, additionally failed to notice they had not effectively selected an answer because the difference between activated and non-activated answers was not accentuated enough (see problem 6 in table 4.2.4).

Use of the stop button

When inexperienced Michelle (56yrs) noticed most of her answers were missing from the summary in question 6, she got confused. In question 6 she was asked to choose the three most important activities in which she was limited. The screen contained only one activity-photo while, in her mind, she had selected a lot of photo's earlier. Except for the one photo that she had managed to select, she had tapped on the text beneath the photos, in which case the item was not activated (see problem 5 in table 4.2.4). The activity on the one photo that she had managed to select was of no priority to her. Therefore, she decided to use the stop button and ended the questionnaire.

Inexperienced Bill (72yrs) had a lot of trouble operating the questionnaire. He commented on the introduction clip:

"I do not think that what she is saying is difficult, but I just am not able to remember it. I have no experience with these kind of devices. So I forgot what she said right away."

Bill managed to get to question 4 by activating the help function on each screen he entered. When he touched the navigation button to see all the activity-photo's in question 4, the photo gallery moved in a different direction than he had presumed. This startled him somewhat and made him forget that he had to push the next button to go to the next screen (see problem 7 in table 4.2.4). He activated the help function again, but that was of no use anymore. After trying a few buttons without succeeding to go to the next screen he gave up and tapped on the stop button.

Inexperienced Helga (54yrs) operated the digital questionnaire fluently until she had to choose the three activities that were most important to her in question 5. She did not use the navigation function of the photo-gallery and as a result she did not see all her earlier selected activities (see problem 4 in table 4.2.4). She chose the three most important activities out of the five photos that were immediately visible. When she realized what happened she wanted to pause for a moment to find out how she could change her answer. She interpreted the stop button as a 'time-out-function' and was a bit shocked when she found out that she had stopped the questionnaire altogether.

A complete overview of frequency and severity of all problems encountered can be found in table 4.2.4.

Table 4.2.4 Frequency and severity of encountered problems during the completion processes of all participants

Problem	Amount of Participants	Frequency	Severity rating
1. Accidentally skipping a screen by double tapping on the next button	8	16	serious
2. Double-tap on answering option causing activation and deactivation of the answer of choice	1	1	low
3. Skipping a screen by accidentally touching the next button with the palm of the hand	1	1	low
4. Not using the navigation function of the photo-gallery in question 4 causing the participant not seeing all presented response items	2	2	medium
5. Touching the text underneath a photo in question 4 to select an activity instead of touching the photo itself causing the activity not to be selected	3	30	serious
6. Not able to see whether or not a selected answer is activated (not accentuated enough)	8	8	Medium
7. Not knowing how to get to the next screen	1	1	medium
8. Pushing too hard or tapping too soft on the touch-screen causing the touch screen not to respond	11	40	serious
9. Not able to correct a wrong answer	8	13	serious
10. Not reading the text above the photos of question 5 causing the participant to keep on performing the task given with question 4	4	8	medium
11. Not noticing that the multiple NRS-effort scores in question 8 are related to different activities, which by mistake results in identical scores for different activities	1	1	low
12. Scoring the body chart in question 2 mirrored	2	2	low
13. Scoring (serial) questions that do not apply to the participants' situation (forced by the software)	1	4	medium

Amount of problems

Average/high experienced Ellen (32yrs), Sandra (39yrs) and Joline (19yrs) and little experienced Jill (55yrs), Lydia (56yrs) and Christine (39yrs) were able to complete the questionnaire without any problems. The other eighteen participants were not able to operate the questionnaire fluently. In an absolute as well as relative sense,

more participants with no experience in using mobile technology encountered problems during the completion of the DTTSQ than little experienced participants did (see table 4.2.5). Inexperienced participants encountered an average of 3 problems per person, while participants with little experience encountered an average of 2 problems per person. Within the subgroup of average/high experience participants only one person encountered one problem during completion (see table 4.2.5). Eleven participants encountered problem 8, "Pushing too hard or tapping too soft on the touch-screen causing the touch screen not to respond" multiple times (see table 4.2.4). In some cases participants looked startled after problem 8 occurred. In these cases researcher IT encouraged the participant to go on by kindly saying "try again".

Table 4.2.5. Amount of participants encountering each problems per level of experience with using mobile technology

Problem	No experience n=9	Little experience n=11	Average/high experience n=4	Total population N=24
1	5	3	-	8
2	1	-	-	1
3	-	1	-	1
4	1	1	-	2
5	2	1	-	3
6	4	4	-	8
7	1	-	-	1
8	6	5	-	11
9	3	4	1	8
10	2	2	-	4
11	1	-	-	1
12	1	1	-	2
13	-	1	-	1

Efficiency

The twenty-one participants who got to the end of the questionnaire had an average completion time of ten minutes and twenty-five seconds. Inexperienced participants needed more time than little experienced participants did, who in their turn needed more time than average/high experienced participants did (see table 4.2.6).

Table 4.2.6 Completion time of all participants who did not end the questionnaire prematurely

(sub)Population	Mean completion time	Median completion time	Range of completion times
No experience with mobile technology (n=6)	11.38 min	9.38 min	8.2 min – 22.10 min
Little experience with mobile technology (n=11)	10.41 min	9.57 min	6.54 – 18.10 min
Average/high experience with mobile technology (n=4)	7.55 min	7.42 min	5.50 min – 10.26 min
Total population (n=21)	10.25 min	9.43 min	5.50 min – 22.10 min

Satisfaction

All participants were satisfied with the ease of use of the questionnaire. The use of plain language, the way ICT was used and the way the user interface was designed was greatly appreciated by the participants: Inexperienced Dora (77yrs):

"Everything was well described. I am not always able to understand everything, but this went well. I understood what was asked of me."

Little experienced Roger (70yrs):

"I have trouble operating my mobile phone and I own a notebook but don't you ask me how that thing works! I am capable of a lot but I am not technical in that way. [...] This was the first time for me to use a tablet computer. I only had to follow the instructions. I did not have to start it up or open something, it just started working and it shut down by itself. I thought it was easy to work with. Better than when you have to write things down."

Average/high experienced Ellen (32yrs):

"I am a very visual person. And this thing is very visual. [...] Like green is 'no pain' and red is 'a lot of pain'."

All participants were satisfied with the completion time of the DTTSQ.

Satisfied despite encountered problems

Operation problems, regardless of the amount and severity of the problems encountered by each individual participant, did not

influence satisfaction about the ease of use of the questionnaire. Little experienced Francine (61yrs), for instance, was asked how she felt about the fact that the application did not always respond to her touch right away (see problem 8 in table 4.2.4). She encountered this problem thirteen times in total. She lightheartedly answered:

"Oh these are things that happen. I experience the same things with my own computer. My computer refuses to sometimes, so... I think I was just pushing too hard on the tablet sometimes, that's all."

When inexperienced Bill (72yrs), who used the stop button, was asked if he would have preferred a paper-based questionnaire he said:

"No. It took me some time to get used to it but it is easy to use actually."

Expectations exceeded

Nine participants explicitly stated that operating the questionnaire was easier than they had expected beforehand. When inexperienced Ida (66yrs) was confronted with the questionnaire she agitatedly said:

"Never in a million years I believe I can do this. That I can tell you right away."

Noticeably reluctant and nervous she started to complete the questionnaire. When she finished she seemed surprised and relieved. She smiled and said:

"Okay? So this was the questionnaire? [...] Ooooh but this was doable! I thought I would have to look up things and operate it like my grandchildren do."

And then she started laughing out loud and cheerfully asked if anyone would like to have some coffee.

Little experienced Christine (39yrs) was positively surprised too:

"It responds really well. Normally I am not that good with screens, but this is easy. It almost feels like a game! It really responds nicely. Nothing disappears when I touch it. It reacts very calmly but at the same time it is very fast. I really like that it contains photo's instead of drawings. It is instantly clear: these are my activities and that is what they mean by 'sitting down'. You see it right away. I also like the regular summaries. It keeps you on track and enables you to check whether or not you forgot something."

Participants' recommendations for improvement

The most mentioned recommendations for improvement of the usability of the DTTSQ by participants were: shorten the length of the

instructions, accentuate the activated response items and improve the user interface of question 4 by giving participants a complete overview of activities to choose from in one screen, without having to use complicated navigation functions.

DISCUSSION

Principal Results

All participants within this study were very satisfied with the ease of use of the DTTSQ. Nine participants stated that the usability of the application exceeded their expectations. The participants who had no experience with using mobile technology completed the prototype of the DTTSQ less effectively and efficiently than the little - and average/high experienced participants did. In the group of average/high experienced participants only one problem was encountered in total, while the non-experienced participants encountered an average of three and the little experienced an average of two problems per person. Thirteen different kind of problems were encountered during this study. From a cost-benefit perspective four of these problems will need to be addressed during future development of the DTTSQ, because they have the potential to influence the future usage of the tool negatively [41]. The four problems that need to be addressed are: problem 1 'Accidently skipping a screen by double tapping on the next button', problem 5 'Touching the text underneath a photo in question 4 to select an activity instead of touching the photo itself causing the activity not to be selected', problem 8 'Pushing too hard or tapping too soft on the touch-screen causing the touch screen not to respond' and problem 9 'Not able to correct a wrong answer'. Participants also recommended to shorten the length of the instructions and improve the user interface of question 4 by giving participants a complete overview of activities to choose from in one screen, without having to use complicated navigation functions.

Comparison with Prior Work

In earlier studies talking touchscreens were found to be easy to use for people with different levels of education, literacy or digital skills. These conclusions were based on study participants' level of satisfaction with the ease of use of the tool [44,45] or on results on satisfaction combined with the efficiency with which the tool was completed [46-50]. Effectiveness was not, or in case of Vargas et al. very slightly

[45], tested. This is a debatable approach, because Frokjaer et al. consider effectiveness, efficiency and satisfaction as independent aspects of usability and state that it is risky to assume that there are correlations between these aspects [34]. Therefore, according to Frokjaer et al. satisfaction and efficiency outcomes should always be tested in combination with outcomes of effectiveness in order to give a complete and realistic overview of the usability of a tool. The results of the current study confirm the necessity of combining all three aspects of usability during usability studies. All participants in the current study, including participants who were not able to fully complete the questionnaire because of problems they had with operating the application, were satisfied with the usability of the DTTSQ. Looking solely at the results on satisfaction with the ease of use (which were also found in the comparable studies [44-50]) one could make the assumption that the DTTSQ is, usability-wise, ready to be released. Looking at the data found on efficiency within this study one can see that more experienced participants need less time to complete the questionnaire. This seems logical and matches the results of comparable studies [46,49]. In addition the completion-time was acceptable to all participants of the current study. Based on the efficiency results solely one could therefore also conclude that the DTTSQ was ready to be released. Looking at the results on effectiveness and specifically at the severity-rates of the problems that occurred during the response-process though, the researchers of the current study concluded that the usability of the DTTSQ needs to be improved to prevent problem 1, 5, 8 and 9 from occurring before it can be released.

The results of the current study show how difficult it is to strive for 'inclusive design'. A lot of effort was put into developing a tool that is easy to use for potential future users at risk of exclusion from usage of mHealth tools [31]. By choosing a co-design strategy, development of a user friendly tool for people with diverse levels of education, literacy and digital skills was taken a step further than what was done in earlier comparable projects [44-50]. In the other projects users were involved in the evaluation process of the tools, but development was done by designers and health professionals. In spite of the user-centered development approach that was taken during the development process of the DTTSQ, the goal of inclusive design was not reached yet. Looking at the results of the current study the

tool is ready to be released for average/high experienced, but not for less experienced future users. To be able to evaluate the worth of including potential future users at risk of exclusion it would be interesting to be able to compare data on efficiency and effectiveness of talking touchscreens that have been developed earlier. Specifically, because the user-interface and structure of the DTTSQ differs from comparable tools. For instance, the screen of the DTTSQ contains less buttons and operation functions, it does not have a back function, it provides summaries of given answers regularly to the respondent and questions are not automatically read out loud. In addition the design and format of the answer options in the earlier developed talking touchscreens [44-50] does not match the recommendations given by the low literate people that helped to design the DTTSQ [31]. If it would be possible to compare results on effectiveness from the tests of several different kind of talking touchscreens, a lot of insight could be gained in what does and does not work in striving for inclusive design for less skilled users of such tools.

According to Frokjaer et al. relations between the three aspects of usability depend in complex ways on the application domain, use context and user's experience [34]. User's experience may well have been of influence on the satisfaction outcomes of the current study. Eighty-three percent of the total study population had no or little experience in using mobile technology (see table 1 and 2). Limited or no user experience may have caused a form of computer anxiety, resulting in low self-efficacy, which in its turn led to low expectations towards the ease of use of the DTTSQ [51]. Nine out of the twenty-four participants in the current study explicitly stated that operating the DTTSQ was easier than they had expected beforehand. The other participants did not explicitly state this, but their statements on the ease of use could easily be interpreted as such. No participant stated or gave the impression that the ease of use of the DTTSQ was lower than they would have expected. According to the Expectation Confirmation Theory [52] actual performance exceeding the expectations of testers leads to satisfaction among these testers. The more their expectations are exceeded the more satisfied testers will become. Due to the limited user experience of most of the study participants, expectations towards the ease of use of the DTTSQ may have been low, which may have made it easier to exceed them. Especially considering that the DTTSQ was specifically designed to be easy to use for low educated

people who lack the necessary skills to use ICT [31]. Looking at the results of studies that evaluated the satisfaction about the ease of use of earlier developed talking touchscreens, a similar picture of highly satisfied study participants emerges [44-50]. The qualitative results in two of these studies also show that participants' expectations regarding the ease of use of the tested tool were exceeded [44,47] and two other authors report that satisfaction among the study participants was "extremely" and "overwhelmingly" high [45,48]. In all of the comparable studies a large proportion of the study participants had no or limited computer experience [44-50]. It is reasonable to assume that limited computer experience may have led to low expectations regarding the ease of use of the talking touchscreens and therefore, played a role in the high satisfaction outcomes.

Strengths and limitations

It is a strength of this study that all three aspects of usability, instead of just satisfaction and efficiency, were thoroughly tested and that all of the results of the tests were differentiated for none, little and average/high experienced users (which was not the case in the reports of the comparable studies [44-50]). To this date this is the first study on usability of talking touchscreens that has taken this approach. As a result insight was gained into what kind and amount of usability problems are encountered by the most vulnerable group of potential future users.

It is a strength in itself that none as well as little and average/high experienced users of mobile technology were included in the current study. Although recommended in the literature [12,53], to this date there has been an insufficient amount of empirical studies to prove the worth of involving future users at risk of exclusion in the development process of eHealth tools [54]. In a recent review Latulippe et al. found only three studies that involved future users at risk of exclusion in their design and evaluation processes [8]. The current paper contributes to the body of knowledge of inclusive mHealth design which involves active participation of vulnerable potential future users in usability evaluation.

The qualitative TSTI method [32] was chosen for data collection in the current study. This method was never used in a usability study before. The results of the current study show that the TSTI method is suitable to gain insight in the usability of mHealth tools. It helped the researchers to understand not only what kind of usability problems

occurred, but also what caused these problems to occur and what effect encountering the problems had on participants. In addition, this method suited the needs of low educated and low literate participants by not demanding any reading or writing skills from them. A downside of the chosen method is the lack of generalizability of the data.

A limitation of this study was that participants were encouraged by the interviewer to try touching the screen again when they looked startled because it did not react to their initial touch. This may have influenced the results on effectiveness because it is unknown what would have happened if the interviewer would not have interfered. This may vary from no effect, because the participant would have tried it again anyway, to a higher frequency of occurrence of problem 8, to more participants prematurely stopping to complete the DTTSQ because of being under the impression that the application had stopped working. Any kind of interference in the process of usability testing has a direct influence on the effectiveness results and possibly also on the efficiency and satisfaction results and should therefore be avoided.

Conclusions

The usability of the DTTSQ needs to be improved before it can be released. No problems were found with satisfaction or efficiency during the usability-test. Effectiveness needs to be enhanced by 1. making it easier to navigate through screens without the possibility of accidentally skipping one, 2. enable the possibility to insert an answer by tapping on the text underneath a photograph instead of just touching the photograph itself and 3. making it easier to correct wrong answers. Participants additionally recommended to minimize the length of the instructions and present all the answer options of question 4 in one screen.

Directions for future research

During further development of the DTTSQ both the results of the current study and the study on response process of the DTTSQ [36] should be taken into account simultaneously. The usability and the response processes will have to be re-tested in exactly the same manner after adjustments in the DTTSQ have been made. This process will have to be repeated until an acceptable level of usability and face validity of the DTTSQ is reached. The next step in research should be quantitative usability-, validity- and reliability testing producing

generalizable data.

Considering the difference in amount of problems encountered by none and little experienced participants versus average/high experienced participants within the current study, it can be concluded that in striving for inclusive design it is vital to involve potential future users at risk of exclusion during further development and testing of the DTTSQ. Selecting quantitative methods for this purpose may be quite challenging, because the researchers will have to develop a quantitative study design which will enable people with low literacy skills and low educational levels to participate. Research designs that include reading and writing tasks for participants are ineligible because these tasks may lead to exclusion of these vulnerable and hard to reach populations [55].

Researchers who want to investigate the usability of mHealth tools in populations that include little or inexperienced participants should take into account that the expectations of these participants may easily be exceeded resulting in high participant satisfaction outcomes regardless of the effectiveness and efficiency with which the tool is used. Satisfaction outcomes are influenced by the expectations participants have prior to the test. It could be interesting to measure and further investigate computer-anxiety and self-efficacy towards the use of the tested tool prior to and after usability testing in order to be able to put satisfaction outcomes into perspective.

Further research is necessary to gain more insight into the needs, preferences, capacities, values, and goals in relation to mHealth technology of people with low literacy skills, low educational levels and no or little experience with using mobile technology. Insight is also needed into what effects meeting these user requirements will have on actual future use of these tools by these specific populations.

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Conflicts of Interest

None declared.

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4.3

Usability of the Turkish translation of the Dutch Talking Touch Screen Questionnaire for physical therapy patients with a Turkish background; qualitative study

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ABSTRACT

Background

The Turkish translation of the Dutch Talking Touch Screen Questionnaire (TTSQ) has been developed to help physical therapy patients with a Turkish background in the Netherlands to autonomously elucidate their health problems and impairments and set treatment goals, regardless of their level of health literacy.

Objective

The aim of the current study was to evaluate the usability (defined as effectiveness, efficiency and user satisfaction) of the Turkish TTSQ for physical therapy patients with a Turkish background with diverse levels of health literacy and experience in using mobile technology.

Methods

The qualitative Three-Step Test-Interview method, including both think-aloud and retrospective probing techniques, was carried out to gain insight into the usability of the Turkish TTSQ. Ten physical therapy patients participated. The interview data were analyzed using a thematic content analysis approach aimed at determining the accuracy and completeness with which participants completed the questionnaire (effectiveness), the time it took participants to complete the questionnaire (efficiency), and the extent to which the participants were satisfied with the ease of use of the questionnaire (satisfaction). The problems encountered by the participants in this study were given a severity rating which was used to provide a rough estimate of the need for additional usability improvements.

Results

No participant in this study was able to complete the questionnaire without encountering at least one usability problem. A total of 17 different kinds of problems were found. Based on their severity score, three problems which should be addressed during future development of the tool were: 'Not using the navigation function of the photo gallery in Question 4 causing the participant to not see all presented response items'; 'Touching the text underneath a photo in Question 4 to select an activity instead of touching the photo itself, causing the activity not to be selected'; and 'Pushing too hard or tapping too softly on the touch screen causing the touch screen to not respond'. The

data on efficiency within this study were not valid and are therefore not reported in this article. No participant was completely satisfied or dissatisfied with the overall ease of use of the Turkish TTSQ. Two participants with no prior experience of using tablet computers felt that, regardless of what kinds of improvement might be made, it would just be too difficult for them to learn to work with the device.

Conclusions

As with the Dutch TTSQ, the Turkish TTSQ needs improvement before it can be released. The results of the current study confirm the conclusion of the Dutch TTSQ study that participants with lower levels of education and less experience in using mobile technology are less able to operate the TTSQ effectively. The bilingual setting has had a negative effect on data collection in the current study.

Key words: mHealth; eHealth; surveys and questionnaires; physical therapy specialty; qualitative research

INTRODUCTION

In the past three decades, health care provision in the Netherlands has evolved from a paternalistic to a patient-centered care (PCC) approach. Since 1995, the government has introduced a series of laws and regulations aimed at increasing the autonomy and self-determination of patients [1]. Even today, policymakers, institutions and health-care professionals strive to further develop shared decision-making and self-management in patients. Patients are increasingly expected to behave as active partners in encounters with health-care professionals [2]. Not all patients are able to take on such a role. An important undermining factor is inadequate health literacy [3,4,5], which applies to 36% of the Dutch population [6].

Health literacy is defined as the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain health [7]. The concept contains cognitive and non-cognitive aspects [8]. Cognitive aspects are referred to as 'the capacity to think' and comprise functional skills like literacy, numeracy and information processing. Non-cognitive aspects are referred to as 'the capacity to act', and comprise skills such as goal-setting, making a plan and

taking action [9]. Having the capacity to think and to act are equally important preconditions for patients' taking on a pro-active role during encounters with health professionals [8]. The majority of health literacy interventions, however, are aimed at improving cognitive skills [10,11,12,13,14,15,16,17,18]. To create a successful health literacy intervention, developers should: (a) try to best fit the needs of persons with inadequate health literacy by incorporating members of the target group into their design team and (b) focus on non-cognitive, as well as cognitive, aspects of health literacy [11]. Based on the results of current research, the possibilities of training non-cognitive skills are expected to be limited [9]. This may mean that interventions aimed at increasing 'the capacity to act' should not be focused on *training* non-cognitive skills but on *supporting* them. This was exactly what the initiators of the development of the Dutch Talking Touch Screen Questionnaire (Dutch TTSQ) had in mind [19].

The Dutch TTSQ has been developed to help Dutch physical therapy patients, regardless of their level of health literacy, to elucidate their health problems and impairments and set treatment goals. Ten low literate persons were involved in the development process of the prototype. In the Dutch TTSQ, which runs on a tablet computer, plain language and self-explanatory scales were used, alternatives to text were offered (e.g., audio, pictures, and clips), and easily accessible background information on the questionnaire's rationale was provided. The development of the prototype of the Dutch TTSQ was described in detail by Cremers et al. [19]. It was pre-tested for usability [20] and face validity [21]. The results of both studies were promising but showed the need for further development.

Alongside the Dutch version, a Turkish version was developed. Development of this was seen as a starting point for development of other language versions. The initiators started with the Turkish version because people with a Turkish background form the biggest minority group in The Netherlands (about 400,000 people, 2.3% of the total population) [22]. Approximately one-third of the Turkish people between 15 and 65 years of age in the Netherlands only went to primary school, compared with 6% of the Dutch majority population [23]. The proportion of Turkish people with low literacy and low health literacy is unknown but, since education and literacy are very strongly associated [24,25], one can assume that low literacy and low health literacy are

over-represented in the Turkish minority group. Most people with low literacy are not digitally skilled [26] and recent studies found ethnic and socioeconomic differences in the use of mobile technology [27,28]. Therefore, it is to be expected that a relatively large proportion of this target population has little experience of using mobile technology. This may be a complicating factor in the use of the Turkish version of the TTSQ.

The aim of this study was to test the prototype of the Turkish TTSQ within the physical therapy context to see which parts of the prototype needed adjustment to increase user-friendliness for physical therapy patients with a Turkish background, regardless of their level of health literacy or experience of operating mobile technology.

The research question underlying this study was: What is the usability of the prototype of the Turkish TTSQ for physical therapy patients with a Turkish background with diverse levels of health literacy and experience in using mobile technology?

METHODS

Design

A qualitative descriptive case study [29] was carried out. Data were collected and analyzed as in the study on ease of use of the Dutch version of the TTSQ [20]. Data on the way participants operated the Turkish TTSQ were collected through the Three-Step Test-Interview (TSTI) method [30]. This method includes both think-aloud and retrospective probing techniques.

Definitions

Usability was defined by the International Standards Organization (ISO) as "the effectiveness, efficiency and satisfaction with which specified users can achieve goals in particular environments" [31].

Effectiveness is the accuracy and completeness with which users achieve certain goals [32]. In this study, rates and severity of problems were used as primary indicators of effectiveness.

Efficiency is the relation between the accuracy and completeness with which users achieve certain goals and the resources expended in

achieving them [32]. In this study, task completion time was used as an indicator of efficiency.

Satisfaction is the users' comfort with and positive attitudes towards the use of a system [32]. In this study, participants were interviewed about their satisfaction with the ease of use of the Turkish TTSQ. Ease of use was defined as the degree to which the use of a particular system is free from effort [33].

Setting and Participant Selection

Recruitment took place in twelve primary care practices in deprived areas of Utrecht, The Netherlands. Potential participants were invited by their physical therapist to participate in this study. Researcher SB was a native Turkish speaker with a Turkish background and employed as a physical therapist in one of the recruiting practices. No other recruiting therapists had Turkish backgrounds or spoke Turkish. Each recruiting therapist shortly explained the goal of the study to potential participants and provided them with Turkish and Dutch versions of a flyer and information letter. The flyer contained a brief summary of the background and goal of the research project and an invitation to its readers to read more about the project in the accompanying information letter. Both versions of the flyer and information letter were written in plain language. If patients were interested in participating, their therapist asked permission to give their contact information to the researchers. If patients spoke and understood Dutch, researcher MW contacted them by telephone; otherwise, researcher SB contacted them. During the telephone conversation, the researchers invited questions, checked that patients understood what was being asked of them, and checked that inclusion criteria were met. Inclusion criteria were: aged 18 years or older, able to understand the Turkish language, and both parents born in Turkey. The sampling procedure was aimed at getting a sample of 6-12 participants, typical for formative usability testing of devices like the TTSQ [34] because it would reveal the most important points needing improvement for further development of a tool without the risk of unnecessary expenditures [35]. Data collection was stopped when a good balance was reached in terms of age, gender, level of education, level of functional health literacy, and prior experience with using a tablet computer. Throughout the recruitment process, the recruiting physical therapists were constantly kept informed about the profiles

of participants the researchers were looking for.

Content of the Turkish Talking Touch Screen Questionnaire

The prototype of the Turkish TTSQ (see Appendix 2) is a direct translation of the Dutch TTSQ (see fig 4.3.1 and 4.3.2) [19,20,21], which is described in detail in the methodological sections by Welbie et al. 2018 and 2019 [20,21].

Translation of the Dutch TTSQ into Turkish was done by a native Turkish speaker who worked as a Turkish language teacher in the Netherlands. Comprehension of the translated text was tested by researcher TC, a native Turkish speaker with a Turkish background. She asked seven non-Dutch speaking women, who were born in Turkey and now lived in the Netherlands, to read the written text, listen to the spoken text in the Turkish TTSQ and explain to her what they thought was meant by the questions and answer options. The seven women had finished primary school at most and were following different kinds of courses (like cooking and handicraft) together at a mosque in Utrecht. The seven Turkish female testers had no problems understanding both spoken and written text. An overview of all types of screens is given in Fig. 1 – 16 in Appendix 2. The eight questions of the questionnaire can be found in Fig. 2, 3, 4, 7,9,11,12 and 13 of Appendix 2.

4.3



Figure 4.3.1 Screenshot Dutch TTSQ 'overview most important activities'



Figure 4.3.2 Screenshot Turkish TTSQ 'overview most important activities'

Data collection and procedures

Data collection took place at the physical therapy practice or the participant's home, depending on the preference of the participant. Researchers MW and SB were present. Researcher MW was in the lead during the interviews. She communicated in Dutch during the whole meeting. Researcher SB functioned as an observer as well as an interpreter when participants spoke Turkish. As an interpreter-researcher, SB did not interfere in the conversation, but solely acted as an intermediary. Participants spoke Dutch, Turkish, or a mixture of both languages, depending on their preference and abilities. At the end of the interview, researcher SB asked complementary questions if some information was lacking. When SB asked these questions in Turkish, he directly translated them and later the answers given by the participants into Dutch so that researcher MW could closely follow what was said.

The following data-gathering steps were taken according to the TSTI method [30]:

Step 1

All participants were observed by researchers MW and SB while they were completing the Turkish TTSQ. During the completion of the questionnaire, they thought out loud. When participants spoke Turkish or used some Turkish words, researcher SB took on the role of interpreter and translated the text into Dutch. This step was aimed at

collecting observational data on the usability of the Turkish TTSQ. The data collected consisted of two types: 1. observations of participants' behavior; and 2. think-aloud data. A video recording was made of this interview step. The video camera was aimed at the tablet computer and the hands of the participant while operating the screen. Additionally, both researchers MW and SB took real-time notes for use during the following steps of the interview, as well as for later analysis. The researchers wrote their notes down on hard copies of screenshots of the Dutch TTSQ, which were printed next to the identical screens of the Dutch questionnaire so researcher MW was able to read the question and answer options in Dutch. Researchers MW and SB noted problems with operating the tablet computer, including using the touch screen, navigating through the questionnaire, understanding the task given in each screen, selecting response items, using the correction function, and use of the stop and help buttons.

4.3

Step 2

Researcher MW interviewed each participant after they had finished completing the Turkish TTSQ. Data collection during this step was exclusively focused on filling possible gaps and checking the observational data collected during Step 1. An audio recording was made of this interview step.

Step 3

During Step 3 of the TSTI, researcher MW conducted a semi-structured interview aimed at eliciting experiences and opinions of participants. At the end of the interview, researcher SB asked complementary questions, if he felt it was necessary, in order to get complete and rich data. When participants encountered problems in operating the Turkish TTSQ, they were asked what they thought the exact nature and possible cause of each type of problem was. Additionally, they were asked how they tried to overcome the problem and if they had suggestions for making it easier to operate the Turkish TTSQ at this point. Then the participants were questioned about their satisfaction regarding the overall ease of use of the Turkish TTSQ. The participants were encouraged to report feelings, express opinions, state preferences and make recommendations. An audio recording was made of this interview step.

When the interview was finished, demographic data, data on self-reported experience with using a tablet computer, self-reported health, and Functional Health Literacy measured with the Set of Brief Screening Questions – Dutch version (SBSQ-D) [36] were collected (see Tables 4.3.1 and 4.3.2). The SBSQ-D is the Dutch version of Chew's SBSQ. This tool consists of the following three statements: "How often do you have someone help you read hospital materials?"; "How confident are you filling out medical forms by yourself?"; and "How often do you have problems learning about your medical condition because of difficulty understanding written information?" The combined item-responses result in a subjective health literacy score [37,38]. The SBSQ-D was conducted orally by researcher SB who translated the statements into Turkish if necessary.

Analyses

Data were analyzed using a thematic content analysis approach [39]. Four types of data were analyzed: 1. video recordings of the completion of the questionnaire; 2. field notes of the observed participant behavior; 3. transcriptions of the Dutch spoken text within the video and audio recordings; and 4. background information regarding educational level, level of literacy, age, gender, and prior experience using a tablet computer.

Only the *Dutch* spoken text within the interviews was transcribed. After transcription, researcher TC listened closely to the recordings while looking at the transcriptions of the Dutch spoken text. When she disagreed with the translation made by researcher SB during the interview, she added what she thought was a more accurate translation to the transcript in a different color. Then researcher TC and SB sought consensus on the most accurate translation.

Researcher MW started the coding process by coding Step 1 of the interview directly on the video recordings, using MAXQDA 12 of VERBI Software GmbH, Berlin. This was partly an inductive and partly a deductive process. The deductive process consisted of using the descriptions of the thirteen usability problems found in the ease of use study of the Dutch TTSSQ [20] as codes. The inductive process comprised open coding of new problems, statements of the participants about the cause of these problems, and the way they thought these problems could be avoided in the future. In addition, statements of participants

about satisfaction regarding the ease of use of the Turkish TTSQ were coded and completion times were registered. After researcher MW finished coding Step 1 for one interview, she checked from the transcription of Steps 2 and 3 of that interview whether the problems were described and spoken about in a way congruent with her analysis of Step 1. If not congruent, she watched the video again to see if her initial codings for Step 1 needed adjustment. Additionally, she coded the statements participants made during Steps 2 and 3 about the causes of problems during completion of the Turkish TTSQ and the ways they thought these problems could be avoided. She also coded all statements of participants about satisfaction with ease of use of the Turkish TTSQ.

4.3

Directly after coding all three parts of an interview, researcher MW made a descriptive summary of that interview. Each summary contained information on: whether or not the questionnaire was fully completed; if, when and why the stop function was used; if, when and why the help function was used and whether this was effective; the kinds of problems that occurred with the operation; the completion times; and all emerging themes regarding satisfaction with ease of use of the questionnaire. The themes emerging in the summaries were supplemented with related field notes and information regarding educational level, health literacy level, age, gender and experience in using mobile technology. Then researcher MW compared this summary with that made at the end of the interview to check for inconsistencies. If any were found, she looked at all related data again to see if her interpretation and coding of what had happened and was said during the interview needed adjustment.

As the last step of the content analysis, researcher SB took on the role of peer debriefer to test the emerged hypotheses and see if they were reasonable and plausible to him. In order to get a good understanding of how the hypotheses emerged, researchers MW and SB looked at the summaries, codes and raw data (transcripts and videos) together. During their conversation, they constantly and explicitly reflected on the influence their Turkish and Dutch backgrounds might have had on their views on the data and whether or not this made their interpretations of the data differ at any point.

As a next step, researcher MW extracted the observed usability problems from the summaries. MW re-analyzed the video recordings to see how many times each problem had occurred in total and per participant. After a full overview of problems had emerged, she categorized the problems as low, medium, serious or critical, as described by Nielsen and Loranger [40]. The scoring method was described in detail in Welbie et al. 2019 [20]. Nielsen and Loranger recommend tackling only serious and critical problems during the development of a digital tool, because those of low and medium severity are not worth tackling from a cost-benefit perspective. Serious and critical problems, however, can be so disruptive that they make users stop using a tool or prevent them from even starting to use it [40].

Finally, researcher MW ordered the analyzed data into two groups: data from participants who did and did not have experience in using tablet computers. This was to see whether data differed within and between these groups.

During the whole course of the study, procedures, coding, analysis steps and interpretation decisions were discussed with researchers HW and WD.

Transcripts were made in the Dutch language. Only quotes used in the current paper were translated from Dutch into English by researcher MW and checked by researcher HW, who is a bilingual speaker.

Ethics

No external funding was received by the Utrecht University of Applied Sciences to conduct this study. This study was registered with the Medical Ethics Committee of the Academic Medical Centre of Amsterdam which declared that it does not fall under the scope of the 'Medical Research Involving Human Subjects Act'. The study was conducted according to the principles of the Declaration of Helsinki [41]. All participants provided written informed consent. The participants' names used in this article are all fictitious in order to protect their privacy.

RESULTS

A total of ten physical therapy patients were included in this study. Characteristics of the study population can be found in Tables 4.3.1 and 4.3.2.

Table 4.3.1 Characteristics of study population

Characteristics	Study population (n = 10)
Mean age (range) years	53 (35-74)
Gender, n	
Male	6
Female	4
Level of education, n	
Low ^a	4
Moderate ^b	4
High ^c	2
Functional Health Literacy Level measured with SBSQ-D [Fransen et al. 2011]	
Adequate	5
Inadequate	5
Prior experience operating a tablet computer, n	
Yes	5
No	5

^a Low = none or at most finished primary education

^b Moderate = lower secondary education, (upper) secondary education or post-secondary non-tertiary education (including vocational education)

^c High = tertiary education (bachelor's degree or higher)

Table 4.3.2 Characteristics per participant

Pseudonym	Gender	Age (y)	Level of Education	Functional health literacy level measured with SBSQ-D (Fransen et al. 2011)	Self-reported health status	Prior experience using a tablet computer
Meryem	f	74	Low ^a	Inadequate	Poor	No
Mert	m	71	Low ^a	Inadequate	Poor	No
Ceyda	f	65	Low ^a	Inadequate	Satisfactory	No
Gizem	f	44	Low ^a	Inadequate	Poor	Yes
Memhet	m	59	Moderate ^b	Inadequate	Good	No

table continues

Pseudonym	Gender	Age (y)	Level of Education	Functional health literacy level measured with SBSQ-D (Fransen et al. 2011)	Self-reported health status	Prior experience using a tablet computer
Berat	m	38	Moderate ^b	Adequate	Satisfactory	Yes
Elif	F	40	Moderate ^b	Adequate	Good	Yes
Eren	m	48	Moderate ^b	Adequate	Good	No
Imraam	m	52	High ^c	Adequate	Good	Yes
Onur	m	35	High ^c	Adequate	Good	Yes

^aLow = none or at most finished primary education

^b Moderate = lower secondary education, (upper) secondary education or post-secondary non-tertiary education (including vocational education)

^c High = tertiary education (bachelor's degree or higher)

Effectiveness

Two out of the ten participants managed to complete the questionnaire fully. Both had prior experience with operating tablet computers (see Table 4.3.3). Ceyda (65y) and Meryem (74y) left all questions open and Mehmet (59y) stopped completing the questionnaire at Question 5. All three were inexperienced in operating tablet computers. Inexperienced Eren (48y) and Mert (71y) and experienced Imraam (52y), Elif (40y) and Gizem (44y) went through the whole questionnaire but unintentionally left one or more parts incomplete.

Table 4.3.3. Prior experience with using a tablet computer in comparison with ability to fully complete the Turkish TTSQ

(sub)population	not fully completed	fully completed
No prior experience using a tablet computer (n = 5)	5	0
Prior experience using a tablet computer (n = 5)	3	2
Total population (n = 10)	8	2

Unintentionally unanswered (parts of) questions

Inexperienced Eren (48y) and Mert (71y) and experienced Imraam (52y), Elif (40y) and Gizem (44y) failed to fully complete the Turkish TTSQ

because they failed to select answer options and/or unintentionally skipped questions because of problems like tapping on the text underneath a photograph instead of on the photograph itself and by double-tapping on the next button (see Problems 1, 3, 4 and 5 in Table 4.3.4). None of the participants noticed they had failed to select answer options or skipped questions while they were completing the questionnaire.

Stopped completing prematurely

Inexperienced Ceyda (65y) read the first question 'Do you have pain' (see appendix 2, screenshot 2 'Pain'). She was very doubtful about what answer would be right because her pain had decreased since her first physical therapy visit. She gave back the Turkish TTSQ to the researcher without answering the question because she was not able to decide on her answer and skipping the question was not a possibility. Afterwards, during interview Step 3, she told the researcher that she did not know that the red square with 'yes' in it and the green square with 'no' in it were 'buttons' which she could have tapped to insert an answer.

Inexperienced Meryem (74y) did not know what to do with the tablet. She read the first question and then spoke directly to researcher MW to give the answer. When the researcher asked her what she thought she should do next, she answered:

"Well, I hope to benefit from the therapy. That's what I am going for."

When the researcher then asked her if she had any idea what she should do with 'the screen,' she seemed to get somewhat nervous and almost whispered:

"I don't know, I do not know what to say".

Inexperienced Memhet (59y) managed to get to Question 4 without encountering any serious or critical usability problems. In this question, he was asked to select photographs of activities in which he was limited (see appendix 2, screenshot 7 'Activity 'lying'). Memhet tapped on the text beneath the photographs most of the time instead of on the given photographs. He did not notice that this was not sufficient to select the answering option and therefore thought that he had selected far more photos than he actually had. In Question 5, he was asked to select the three activities that were most important to him

out of those he selected in answer to Question 4 (see appendix 2, screenshot 9 'Most important activities'). Because most of his answers had not actually been 'selected,' he only saw a fraction of his 'activity selection'. This confused him. He thought he had misunderstood the question. He did not know how to answer it. After he unsuccessfully tried to skip the question by tapping on the 'next' button, he stopped completing the questionnaire by handing it back to the researchers.

Frequency and severity of problems encountered

Even though two participants were able to complete the Turkish TTSQ fully (see Table 4.3.3), no participant completed it without encountering any problems. A complete overview of the frequency and severity of all problems encountered during operation of the Turkish TTSQ can be found in Table 4.3.4.

Table 4.3.4. Frequency and severity of problems encountered during the completion processes for all participants

Problem	Number of participants who encountered the problem	Number of times the problem occurred	Severity rating
1. Accidentally skipping a screen by double-tapping the 'next' button	2	2	low
2. Double-tapping an answering option causing activation and deactivation of the answer of choice	0	0	-
3. Skipping a screen by accidentally touching the next button with the palm of the hand	0	0	-
4. Not using the navigation function of the photo gallery in Question 4 causing the participant to not see all response items	5	22	serious
5. Touching the text under a photo in Question 4 to select an activity, instead of touching the photo itself, causing the activity not to be selected	4	10	critical
6. Not able to see whether or not a selected answer is activated (not accentuated enough)	1	1	low

7.	Not knowing how to get to the next screen	0	0	-
8.	Pushing too hard or tapping too softly on the touch screen so that it does not respond	8	19	serious
9.	Not able to correct a wrong answer	3	3	medium
10.	Not reading the text above the photos in Question 5, causing the participant to continue the task given in Question 4	1	1	low
11.	Not noticing that the multiple numeric rating scale 'effort' scores in Question 8 are related to different activities, which in error results in identical scores for different activities	1	1	low
12.	Mistakenly scoring the mirror image in the body chart in Question 2	1	1	low
13.	Scoring (serial) questions that do not apply to the participants' situation (forced by the software)	0	0	-
14.	Using navigation function Question 4 to try to get to the next screen.	2	2	low
15.	Not knowing how to enter an answer into the TTSQ	2	2	medium
16.	Not being aware of the existence of the 'help' function	2	2	medium
17.	Entering more than one answer into an NRS causing the TTSQ to select only the last entered answer	2	2	low
18.	Activating the 'stop' function accidentally by touching it with the palm of the hand holding the tablet	1	2	medium

Efficiency

Because of the need to translate the 'spoken out loud thoughts' of participants into Dutch, the completion time was lengthened. As a result, the collected data on efficiency were not valid and will not be reported in this article.

Satisfaction

Positive remarks

No participant was distinctly positive or negative about the overall ease of use of the Turkish TTSQ. Five out of ten participants made

positive remarks on the way the user interface was designed and on the short completion time.

Experienced Imraam (52y) said:

"These visual images are appealing and make it 'come to life'".

Experienced Onur (35y) was positive about the regular overviews of given answers and inexperienced Eren (48y) was positive about the short length of the questionnaire.

Recommendations for improvement

Nine out of ten participants formulated recommendations for improvement. Most mentioned were: improve accentuation of the activated response items; give a complete overview of activities to choose from in answer to Question 4; and shorten the instruction clips by limiting the information to the main issues.

Inexperienced Seyda (65y) and Meryem (74y) had trouble concentrating on the information in the introduction clip, as did others. But they were not sure if limiting the amount of information or length of the clip was going to help them. They felt it would just be too difficult for them to learn to work with the Turkish TTSQ, regardless of improvements on its usability. They linked their lack of ability to comprehend and remember the instructions given on their lack of experience with operating tablet computers, their older age and their health status.

Experienced Berat (38y) recommended limiting the text above the overviews. For example, he suggested deleting the first sentence from the text: "On this screen you see all the activities that you selected in previous screens. These are the activities in which you are limited. Is that right?" (see appendix 2, screenshot 8 'Overview activities').

Berat also would have liked to the opportunity of completing the Dutch version of the Questionnaire because, as he said:

"My Turkish is good but my Dutch is better."

Some participants suggested adding more advanced options to the Turkish TTSQ. Experienced Onur (35y) and Berat (38y) recommended a swipe function for the screens that contained rows of activity photos. Experienced Elif (40y) would have liked to see muscles in the body chart so she would be able to indicate the location of her pain more

precisely. Like Elif, Onur and inexperienced Eren (48y) also wanted to be able to indicate the locations of their complaints more precisely, but they suggested a function that would enable them to zoom in on a specific body part.

DISCUSSION

Principal results

Two participants, who had prior experience with using tablet computers, managed to complete the questionnaire fully without leaving any parts unanswered. No participant in this study was able to complete the questionnaire without encountering a usability problem. A total of 17 different kinds of problems were found. Three problems should be addressed during future development of the tool based on their severity score [40]: 'Not using the navigation function of the photo gallery in Question 4 causing the participant to not see all presented response items', 'Touching the text underneath a photo in Question 4 to select an activity instead of touching the photo itself causing the activity not to be selected' and 'Pushing too hard or tapping too softly on the touch screen causing the touch screen to not respond'.

No participant was distinctly satisfied or dissatisfied about the overall ease of use of the Turkish TTSQ. Positive remarks were mainly made on the user interface and the short completion time of the Turkish TTSQ. The most frequently-made recommendations were: improve accentuation of the activated response items; give a complete overview of activities to choose from in answer to Question 4; and shorten the instruction clips by limiting the information to the main issues. Two inexperienced participants felt that, regardless of what improvements might be made, it would just be too difficult for them to learn to work with the device.

Strengths and limitations

A strength of this study was the inclusion of ten members of a target population that is generally 'hard to reach' for researchers [42]. Researcher SH played an important role in the recruitment and data collection within this study. His Turkish background and him being a native Turkish speaker, combined with his network, status and trustworthiness as a physical therapist working in the community, may have had a positive influence on the willingness of potential candidates

to participate in this study [43]. This hypothesis is reinforced by the fact that, although recruitment was done in twelve different physical therapy practices, eight out of ten participants were recruited in the practice where researcher SH was employed.

The positive effect researcher SH had on the sampling procedure may also have had a downside. In spite of all efforts of the researchers to inform potential participants thoroughly and make sure that participation was done voluntarily, the authority of researcher SH as researcher and physical therapist [43] may have caused participants to agree to participate too quickly without really foreseeing what was being asked of them. The majority of the participants seemed to have 'a lot on their plate' and were therefore not able to entirely focus on their tasks during the data collection process. Eight out of ten participants reported multiple health problems. One participant even ended the interview prematurely because it became too much for her due to her physical and mental state. Another participant, who reported eleven different kinds of health problems, told the researchers that his biggest problem was not even his health status but his poor financial situation. In hindsight, the researchers got the impression that, for some, participation in this study may have been too much to ask.

The bilingual research setting also brought some limitations to this study. Apart from the translation lengthening the completion time, three participants forgot to insert some of their answers during the completion process, while they *did* formulate their answers when thinking out loud. They all said they would not have forgotten this in a 'real life' physical therapy setting where there would have been no observers or interpreters present and they would not have been asked to think out loud. Three other participants said that the translation limited their ability to concentrate on their task and thoughts. This may have caused participants to make more mistakes than they would have done had the whole interview been in the Turkish language.

Comparison with prior work

Although there is a considerable amount of overlap in the kind and severity of problems encountered in the current and Dutch TTSQ study [20], the participants of the current study encountered different kinds of problems and were less able to complete the questionnaire fully

than those in the Dutch TTSQ study. The explanation for this can be found in the fact that, compared to the Dutch study, the population of this study was less educated, had lower health literacy, and had less experience with using tablet computers. In the current study, no participant was completely satisfied or dissatisfied with the overall ease of use of the Turkish TTSQ, while, in the Dutch TTSQ study, the participants were not only very satisfied but their expectations of ease of use of the tool were exceeded [20]. In contrast to the Dutch TTSQ study, not all Turkish participants had the sense of self-efficacy to be able to complete the Turkish TTSQ, no matter what improvements might be made. The results of the Dutch TTSQ study showed that participants with lower education and less experience in using mobile technology were less able to operate it effectively [20]. This is confirmed by the results of the current study.

Two earlier studies were found in which usability was part of the assessment of a direct translation of a Talking Touchscreen (TT) questionnaire, both published by Hahn et al. [44,45]. In the 2003 study, the usability components 'satisfaction' and 'efficiency' were tested. In this study, thirty Spanish-speaking patients with cancer completed a TT which contained the Functional Assessment of Cancer Therapy-General (FACT-G) [46] and the Short Form-36 Health Survey (SF36) [47]. Fifty percent of the participants had lower than 7th grade education. Satisfaction with ease of use and efficiency were tested by presenting evaluation questions on the use of the TT followed by a short debriefing interview. What is noticeable about the satisfaction and efficiency results is that all thirty participants reported that they thought of the tool as 'very easy' or 'easy to use' and the completion 'did not take too long', while 57% (8/15) of participants with less than 7th grade education and 14% (2/15) of the participants with more than 7th grade education preferred an interviewer orally conducting the questionnaire to use of the talking touchscreen. Hahn et al. interpreted these results in a positive way and reported that *"many patients either preferred using the touchscreen rather than having an interviewer ask the questions, or had no preference"*. While true for the more educated participants, the majority of the less educated participants did not prefer using the TT. Hahn et al. concluded their paper by stating that *"the 'Talking Touchscreen' will allow Latino patients with varying literacy skills to be included more readily in clinical trials, clinical practice research and QOL studies."* This conclusion may be too one dimensional, given

the results they reported and the methods they used. In the other study by Hahn et al., published in 2010, only user satisfaction was tested [45]. In this study, 414 Spanish-speaking patients with cancer were included of which 213 had low levels of literacy. The tested touch screen system contained the FACT-G [46], SF-36 [47] and Standard Gamble Utility Questionnaire (SGUQ) [48]. The methods used to test satisfaction about the ease of use were highly comparable to the earlier study of Hahn et al. [44]. Looking at the quantitative results, one can conclude that, although satisfaction among the majority of the participants was high, low literacy participants were less satisfied with the ease of use of the TT than were those with high literacy. It is hard to compare the results of the studies of Hahn et al. to the results of the current study because, while the participants in their studies could ask for assistance from the researchers during completion of the TT, in the current study participants did not receive any help at all. In the 2003 study, 60% of participants received help from a researcher during completion of TT; how many received help in the 2010 study was not reported. It can be concluded that researchers in the current study tested and reported the usability of their tool much more thoroughly. Although it is difficult to directly compare the results of the Hahn et al. studies with the current studies because of differences in study setups and the detail in which results were reported, the results of both Hahn et al. studies seem to confirm our findings that it is harder for less educated participants to use a TT than for higher educated participants.

Conclusions

Just like the Dutch TTSQ, the Turkish TTSQ needs improvement before it can be released. The results of the current study confirm the conclusion of the Dutch TTSQ study that participants with lower education and less experience in using mobile technology are less able to operate the TTSQ effectively. Although the methodology of the current usability study was very thorough, its bilingual setting has had a negative effect on data collection.

Directions for future research

The aim of the project, of which the current study is part, is to create multiple language versions of the TTSQ to help Dutch physical therapy patients, regardless of their level of health literacy, to elucidate their health problems and limitations, and set treatment goals. The results

of both usability studies of the TTSQ show that this should particularly be improved for the least skilled future users. Therefore, the logical next step is adapting and testing both language versions of the tool solely with inexperienced users who have low literacy. When the pretests show that future users at risk of exclusion are able to complete the Turkish and Dutch versions of the TTSQ fully without encountering serious or critical usability problems, pretests on response processes should be conducted to get a first impression of the face validity of both versions of the questionnaire [49]. Additionally, the equivalence of both language versions should be tested using item response theory [50]. Dependent on the results of these response processes and item response theory studies, cultural adaptation of the Turkish TTSQ may be needed to avoid bias from cultural and linguistic effects on interpretation, retrieval, judgment and response selection, which are the four phases of the response process as described by Tourangeau et al. [51]. Both researchers and participants should communicate in Turkish in all future studies on the Turkish TTSQ to avoid the methodological problems encountered in the current study. Recruitment of participants with a Turkish background should be done by intermediaries with Turkish backgrounds, rather than by the researchers themselves, to limit the chance of people agreeing to participate too easily without foreseeing the consequences of their participation. When the results of all pretests are satisfactory, the last step in research should be quantitative usability, validity and reliability testing to produce generalizable data.

No data on levels of literacy, health literacy or digital skills are available for the Turkish minority group in the Netherlands. Research should be done to get insight into these characteristics and into attitudes towards use of information and communication technology in general and of mHealth technology more specifically within this and other minority groups. Otherwise, these already disadvantaged groups may not be able to profit from the advantages of the use of m- and eHealth technologies [52,53,54]. This may add to the ongoing exacerbation of health inequalities in the Netherlands [55].

It is of great importance to keep striving for the development of TT questionnaires which are user-friendly to low literacy minority patients who have not mastered the native language of the countries in which they are living in. Such tools will greatly facilitate data collection within

these hard-to-reach populations. It will empower vulnerable patients who will be able to give their input to research and clinical practice. And because they will not need help or instructions from researchers or health care providers, it will reduce staff burden, costs and interviewer bias. The use of TT questionnaires may also serve as a way to increase exposure of underserved populations to new technologies and contribute to information about the experiences of diverse populations with these technologies [56]. In order to get reliable and valid test results for the evaluations of these tools, researchers need to keep striving for research setups and methods that fit the needs and abilities of hard-to-reach populations. Publishing positive as well as negative results on usability, reliability and validity and giving as much insight into evaluation methods, study contexts and setups as possible, will help researchers and developers in finding ways to accommodate hard-to-reach populations, and contribute to the body of knowledge on inclusive design-oriented research.

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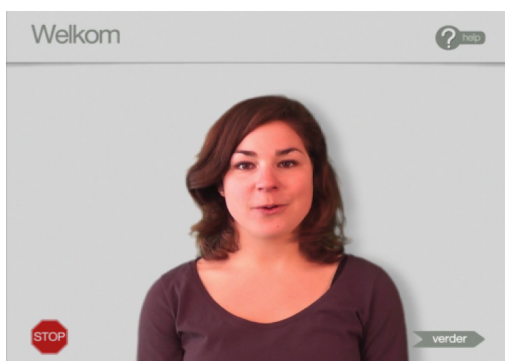
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APPENDIX 1

Screenshots Dutch Talking Touch Screen Questionnaire

Screenshot 1 'Welcome'

Introduction movie



Screenshot 2 'Pain'

Question 1: "Do you have pain? Yes/No"



Screenshot 3 'Location of the health problem'

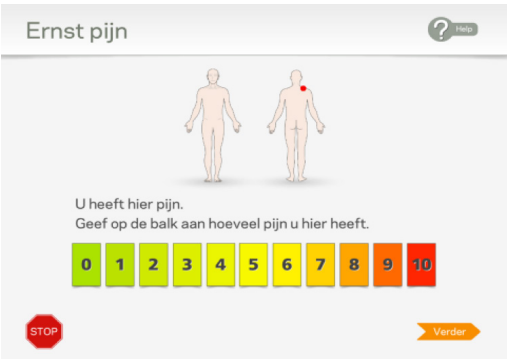
Question 2: "Tap on the location of your health problem. You can tap on multiple locations."



A¹

Screenshot 4 'pain severity'

Question 3: "This is the location of your pain.
Rate the severity of your pain on the scale below."



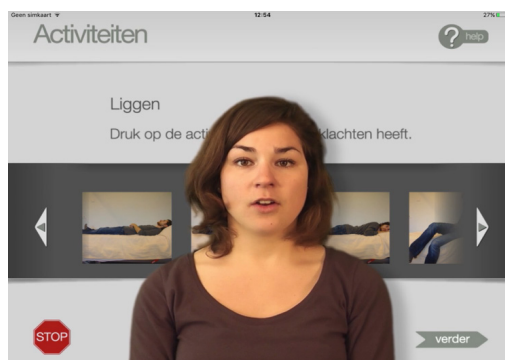
Screenshot 5 'Overview location of the health problems'

Overview answers question 1-3: "This is the location of your health problems."



Screenshot 6 'Activities'

Instruction movie question 4



Screenshot 7 Activity 'lying'

Question 4: "Select the activities in which you are limited"



Screenshot 8 'Overview activities'

Overview answers question 4: "On this screen you see all the activities that you selected in previous screens. These are the activities in which you are limited."

A¹

Screenshot 9 'Most important activities'

Question 5: "Select the three activities which are most important to you"



Screenshot 10 'overview most important activities'

Overview answers question 5: "You chose these three activities. Is this correct?"



Screenshot 11 'Most important activity 1'

Question 6: "Select the activity which is most important to you"



Screenshot 12 'Most important activity 2'

Question 7: "Which of these two activities is still most important for you now?"



Screenshot 13 'Effort activity 1'

Question 8: "Rate the effort it takes to carry out this activity"

Screen screenshot of a mobile application interface titled "Moeite activiteit 1". At the top, there is a status bar with "Groot scherm", "10:32", and "45%". Below the title, there is a question mark icon and a "Help" button. The main content area features an illustration of a person putting on a jacket, with the text "Aankleden of uitkleden" (Dressing or undressing) below it. Below this, the instruction "Geef op de balk aan hoeveel moeite deze activiteit u kost." (Indicate on the bar how much effort this activity costs you.) is displayed. A horizontal bar contains 11 colored squares representing a rating scale from 0 to 10. The squares are colored: 0 (green), 1 (light green), 2 (light green), 3 (light green), 4 (light green), 5 (yellow), 6 (yellow), 7 (yellow), 8 (orange), 9 (orange), and 10 (red). At the bottom left, there is a red octagonal "STOP" button. At the bottom right, there is an orange arrow button labeled "Verder" (Next).

A¹**Screenshot 14 'overview most important activities and effort'**

Overview answers question 6-8: "On this screen you see the activities that are most important to you in order of most important to least important. Is this correct?"

Screen screenshot of a mobile application interface showing an overview of activities. At the top, there is a status bar with "Groot scherm", "10:33", and "45%". Below the title, there is a question mark icon and a "Help" button. The main content area features the instruction "U ziet nu op het scherm de activiteiten die voor u het belangrijkste zijn op volgorde van meest belangrijk naar minst belangrijk. Klopt dit?" (You see on the screen the activities that are most important to you in order of most important to least important. Is this correct?). Below this, there are three activity cards. Each card has a yellow square with a number above it, an illustration of a person performing the activity, and the activity name below it. The first card is labeled "6" and "Aankleden of uitkleden" (Dressing or undressing). The second card is labeled "8" and "Haren kammen" (Combing hair). The third card is labeled "9" and "Reiken" (Reaching). At the bottom left, there is a red octagonal "STOP" button. At the bottom right, there is an orange arrow button labeled "Verder" (Next).

Chapter 4

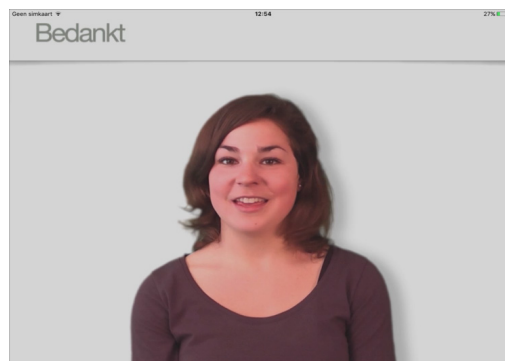
Screenshot 15 'overview all outcomes of the questionnaire'

Overview answers total questionnaire: "On the screen you see an overview of all your answers you provided until now."



Screenshot 16 'Thank you'

Closing movie

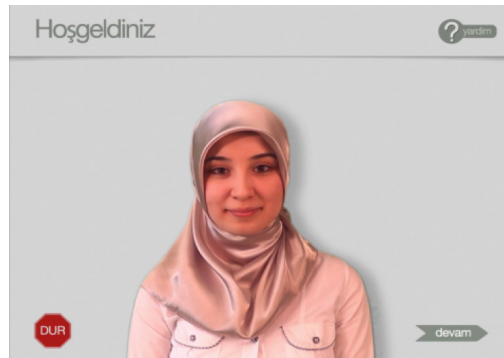


APPENDIX 2

Screenshots Turkish Talking Touch Screen Questionnaire

Screenshot 1 'Welcome'

Introduction movie



Screenshot 2 'Pain'

Question 1: "Do you have pain? Yes/No"



A²

Screenshot 3 'Location of the health problem'

Question 2: "Tap on the location of your health problem. You can tap on multiple locations."

Şikayet bölgesi Yardım

Şikayetinizin olduğu bölgeyi tıklayınız.
Birden fazla bölgeyi tıklayabilirsiniz.

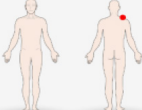


DUR Devam

Screenshot 4 'pain severity'

Question 3: "This is the location of your pain.
Rate the severity of your pain on the scale below."

Ağrı şiddeti Yardım



Bu bölgede ağrınız var.
Ölçek üzerinde bu bölgedeki ağrı seviyesini belirtiniz.

0	1	2	3	4	5	6	7	8	9	10
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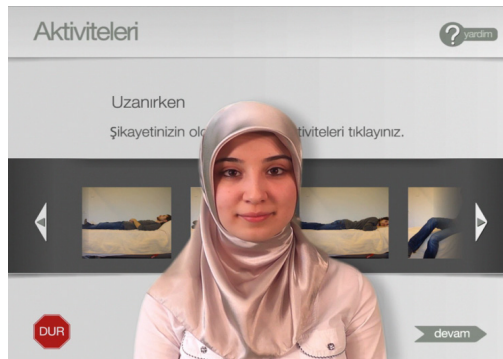
DUR Devam

Screenshot 5 'Overview location of the health problems'

Overview answers question 1-3: "This is the location of your health problems."

**Screenshot 6 'Activities'**

Instruction movie question 4

A²**Screenshot 7 Activity 'lying'**

Question 4: "Select the activities in which you are impaired"



Screenshot 8 'Overview activities'

Overview answers question 4: "On this screen you see all the activities that you selected in previous screens. These are the activities in which you are impaired."



Screenshot 9 'Most important activities'

Question 5: "Select the three activities which are most important to you"



Screenshot 10 'overview most important activities'

Overview answers question 5: "You chose these three activities. Is this correct?"

**Screenshot 11 'Most important activity 1'**

Question 6: "Select the activity which is most important to you"

A²

Chapter 4

Screenshot 12 'Most important activity 2'

Question 7: "Which of these two activities is still most important for you now?"



Screenshot 13 'Effort activity 1'

Question 8: "Rate the effort it takes to carry out this activity"



Screenshot 14 'overview most important activities and effort'

Overview answers question 6-8: "On this screen you see the activities that are most important to you in order of most important to least important. Is this correct?"

A²**Screenshot 15 'overview all outcomes of the questionnaire'**

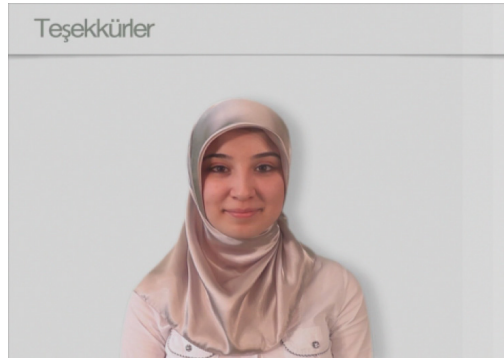
Overview answers total questionnaire: "On the screen you see an overview of all your answers you provided until now."



Chapter 4

Screenshot 16 'Thank you'

Closing movie



CHAPTER 5

General discussion



INTRODUCTION

The aim of the research project described in this thesis was to develop a tool which would help Dutch and Turkish physical therapy patients with inadequate health literacy (HL) to be more able to take an active part in the decision-making process within the diagnostic phase of physical therapy treatment in The Netherlands.

The first objective within this research project was to assess which problems physical therapy patients with diverse levels of HL and Dutch and Turkish backgrounds encountered during completion of the Patient-Specific Complaint questionnaire (PSC) [1,2]. The PSC was taken as a starting point for the development of the tool that was developed during this research project, which was called the Talking Touch Screen Questionnaire (TTSQ). The content of the PSC [1] fitted the goal of helping patients to provide relevant information regarding their health problem to their physical therapist. It aims to make the patient select his or her main limitations in functioning and formulate his or her own specific treatment goals. To assess which problems physical therapy patients encountered during completion of the PSC, cognitive interviews with twenty-five Dutch and twenty-five Turkish physical therapy patients with diverse levels of health literacy were conducted after they completed the Dutch PSC, using the probing technique described by Collins et al. [3]. The results of this study led to the second objective in this research project, which was the development of a working prototype of the Dutch TTSQ. A co-design method was applied during the development of the Dutch TTSQ by involving ten persons with low literacy in the design team from the start of the development process. User involvement in developing the Dutch TTSQ was organized through two focus group sessions (analysis phase), two user walkthroughs (design phase) and a usability test (implementation) with a new group of low literacy persons. The last objective was to test whether the newly-developed Dutch TTSQ generated accurate information on symptoms, limitations and treatment goals of patients with diverse levels of HL in a physical therapy context and to test and compare the usability of the Dutch TTSQ and its Turkish translation. The Three-Step-Test-Interview method [4], containing both think-aloud and probing techniques was used to get insight into the way 24 Dutch and 11 Turkish physical therapy patients with varying health literacy levels were able to operate the

TTSQ and how their answers came about.

The current chapter starts with a summary of the main findings presented within this thesis which are then put into a broader perspective and will be followed by recommendations for further research and development of talking touchscreens for use in clinical practice to support patients with low HL to participate more actively in provider-patient interactions.

MAIN FINDINGS

Chapter 2 presents the results of a qualitative study which describes the problems 50 physical therapy patients with Dutch and Turkish backgrounds and diverse levels of health literacy encountered during completion of the Patient-Specific Complaint questionnaire (PSC) [1,2]; the most frequently used questionnaire by Dutch physical therapists [5]. The results show that all respondents, except one, experienced problems completing the questionnaire. Most problems were related to comprehension of the instructions and questions and this led 24 respondents, most of whom had low HL, to give invalid answers.

Chapter 3 describes the development of the Dutch version of the Talking Touch Screen Questionnaire. Guidelines for designing interactive questionnaires for low literacy persons were derived from the lessons learned during the co-design process which involved 10 persons with low literacy helping to design the TTSQ. This co-design process resulted in a prototype of the TTSQ which was a digital application on the original iPad 1 with a 9.7-inch screen. A tablet computer was found to be the most suitable device to meet the needs of low literacy people since it had the advantages of a computer, but did not look like one and operating it did not require reading or writing skills. Questions on pain location and pain intensity were added to the original questions of the PSC [1,2], because users were primarily interested in reporting their complaints, not their activity limitations. Visual (videos and photos) and auditory (speech technology) support were added to enable participants to see and hear the questions, which were shown on separate screens. Response items could be selected by tapping on the touchscreen and plain language was used in all spoken and written text within the TTSQ. The results of this study show that, apart from the more 'technical' support, it is important to take the social and

psychological aspects of completing questionnaires into account in designing a TTSQ for people with low literacy.

Chapter 4 describes the evaluation of the Dutch and the later-developed Turkish translation of the TTSQ in a physical therapy context.

Chapter 4.1 shows that the use of plain language and information and communication technology (ICT) had a positive effect on the comprehensibility of the Dutch version of the TTSQ. However, it also had some negative effects on the other four aspects of the response process: interpretation, retrieval, judgment, and response selection [6]. Due to the plain language used, some questions lacked detail, which made them multi-interpretable. Multi-interpretation was also problematic in the use of pictures as answer options for limitations in daily activities. Furthermore, showing questions and answer categories in separate screens without a back function caused respondents to lose an overview of the whole questionnaire. This made it harder for them to decide whether they should select an answer or instead go on to following screens in the hope that these would contain more suitable answers. On the other hand, being provided with specific answer options made some respondents fail to actively search their memories and retrieve information about situations in which they were limited because of their health problem. The problems within the response processes led to invalid and incomplete results in 20 of the 24 cases. The participants did not notice the incorrectness and incompleteness of their answers, as witnessed by the fact that all participants reported recognizing themselves in the overall outcomes. No educational group in this research population stood out from the rest in the kind or number of problems that arose. In **Chapter 4.2**, the results of the usability study of the Dutch version of the TTSQ are shown. The data collection for this study was carried out in the same research population at the same time as the data presented in **Chapter 4.1** were collected. Results of the usability study show that all 24 Dutch participants were very satisfied with the ease and efficiency with which they were able to operate the questionnaire. The ease of use exceeded the expectations of the participants. However, the data on effectiveness showed 13 different kinds of problems occurring during operation of the questionnaire. According to the severity rating system of Nielsen & Loranger [7], nine of these problems were not likely to influence future usage of the tool substantially, but four problems needed to be addressed before the Dutch version of the TTSQ could be released. The less educated and less experienced participants were

in using mobile technology, the more problems they encountered. The results of the usability study of the Turkish version of the TTSQ, presented in **Chapter 4.3**, confirm that participants with less education and less experience in using mobile technology were less able to operate the TTSQ effectively. Most of the 11 Turkish participants, who were in general educated to a lower level and less health literate than participants in the usability study of the Dutch version of the TTSQ, were neither distinctly satisfied nor dissatisfied about the overall ease of use of the Turkish TTSQ. Two Turkish participants, who had no prior experience using mobile technology, felt that, regardless of what kind of improvements might be made, it would just be too difficult for them to learn to work with the tool. Seventeen different kinds of problems were found, of which three needed to be addressed during future development of the tool based on their Nielsen and Loranger severity score [7]. Because the research team had managed to recruit very vulnerable participants in terms of educational level, health literacy level, experience with using mobile technology, health and social status, the results of this study gave good insight in how hard it is for this group, not only to handle technology that is new to them, but to participate in a research project in the first place.

In the current **Chapter 5**, the results of the studies described in this thesis are put into a broader perspective by reflecting on the use of questionnaires in clinical practice in general and comparing both the methods used and results found within this thesis to those of other studies on similar tools. Finally, recommendations for clinical practice and future research are provided.

HEALTH LITERACY AND THE USE OF QUESTIONNAIRES

The hypothesis underlying the research project described within this thesis was that adapting and using a questionnaire to help patients with low HL to explicate, order and prioritize their symptoms and limitations would help them to take a more active part in provider-patient interaction during the diagnostic process of physical therapy treatment. This hypothesis was based on one of the pathways Paasche-Orlow and Wolf described in their conceptual model, in which inadequate health literacy, caused by factors such as ethnic background, socio-economic status, language proficiency and age, causes problems within provider-patient interaction which has a negative effect on health outcomes (see fig. 5.1) [8]. The use of PROMs

was a provenly effective way of improving provider-patient interaction and health outcomes [9-14] and the use of Talking Touchscreens (TT) was proven to be an effective way of increasing the ability of low literacy patients to complete health-related questionnaires [15-26]. Therefore, the researchers in the current research project wanted to adapt the most frequently used questionnaire in Dutch physical therapy practice and add TT technology to it in a way which would support Dutch and Turkish physical therapy patients, to explicate symptoms, limitations and treatment goals during the diagnostic phase of their physical therapy treatment process.

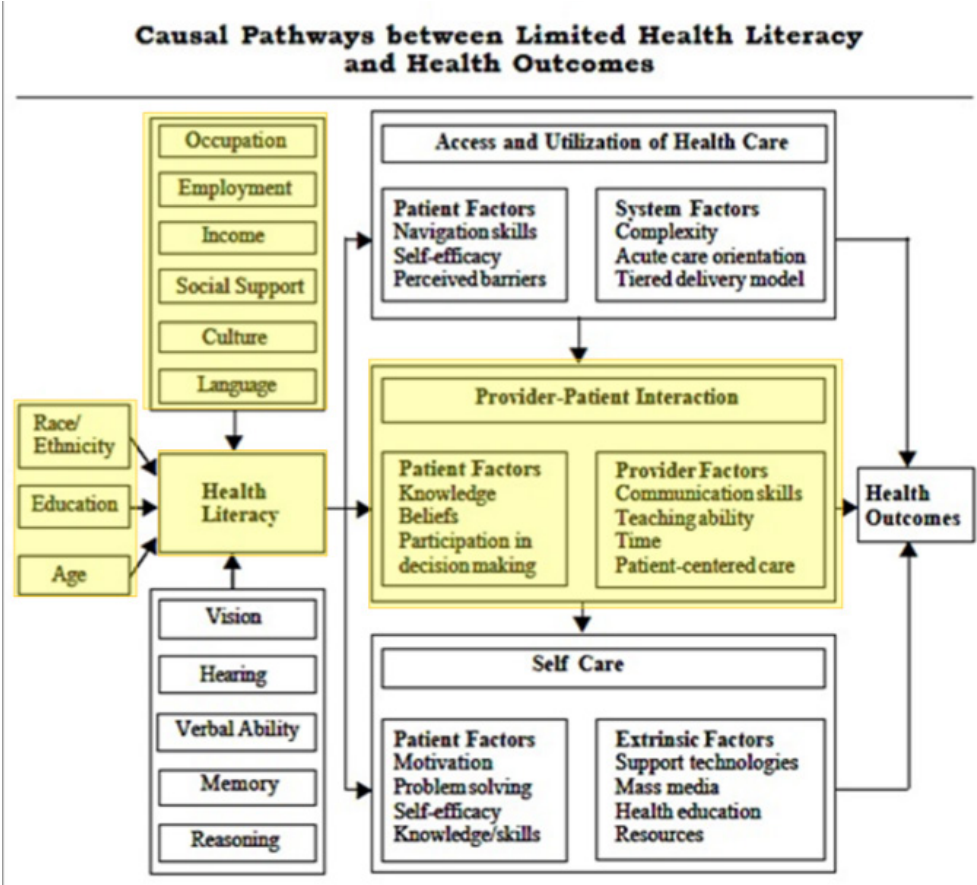


Figure 5.1 Conceptual model of causal pathways between limited health literacy and health outcomes [8]

Nine persons with low literacy with a Dutch and one with a Turkish background joined the design team that would develop the Dutch TTSQ. They informed the other members that having low literacy in an information society like the Netherlands is stressful, because it makes people feel unworthy, unsafe and ashamed in the many situations they encounter in daily life in which too much is being asked of them. Asking a low literacy person to complete a questionnaire does put the person at risk of being exposed as having low literacy, when many of these people are very busy hiding this problem on a daily basis. All of the low literacy designers shared examples of situations in which filling out forms had had a negative effect on their own lives or the lives of someone they knew. They mentioned problems like social welfare being stopped, being visited by child protection agencies, having to pay more taxes, etc. This made them reluctant and anxious when asked to fill out forms. They added that these negative feelings could be strengthened by personal characteristics which, according to them, many people with low literacy, including themselves, develop during the course of their lives, such as being unsure, having low self-esteem and doubting their own judgment. In addition, they expressed the view that being in the vulnerable and dependent position of being a patient could strengthen the stress of having to fill out a questionnaire because refusing to complete a questionnaire could have negative effects on the provider-patient relationship and therefore on the quality of care that the provider is able or willing to give to you as a patient. Additionally, three low literacy designers expressed their view that they thought professionals asked patients to fill out questionnaires to be able to put the blame on the patient in case things go wrong. All of these remarks combined gave the researchers and designers of the current research project the insight that patients with low literacy are not able to take advantage of the positive effects that the use of PROMs can have on the quality of provider-patient interaction and health outcomes [9-14]. Asking low literacy patients to fill out questionnaires can create an unsafe environment for the patient and therefore have negative effects on the patient, provider-patient relationship, and health outcomes. For this reason, a lot of effort was put into the design of the TTSQ to provide users with information on the goal of the questionnaire, the way personal data is handled, the way privacy is guaranteed and to reassure them that there is no time pressure and answers can be adjusted even after the questionnaire is finished. The TTSQ also has an escape button, so users do not feel pressured into completing it. It

has no back function in order to keep users from 'getting lost' in the questionnaire and having to decide on a 'completion-strategy'. This may have had a positive effect on the experience participants had with completing the Dutch version of the TTSQ compared with the experiences participants had with completing the paper-based PSC [1]. A few participants of the study, with both adequate and inadequate health literacy, described in **Chapter 2** of this thesis, expressed negative feelings towards the use of questionnaires in a health care setting after they had completed the paper-and-pencil-based PSC [1]. These results confirmed the negative feelings of patients towards the use of questionnaires which were described earlier in the literature [27-31]. Yet none of the participants in the evaluation studies of the Dutch version of the TTSQ described in **Chapter 4.1** and **4.2** were negative about the use of questionnaires in a health care setting. In fact, a few participants in these studies expressed that they normally did not like to be asked to complete questionnaires, but they did not mind completing this one. They could even think of positive effects which the use of this questionnaire could have on the quality of physical therapy.

The low literacy designers of the TTSQ talked about people with low literacy being insecure, having low self-esteem, being ashamed about and trying to hide their low literacy. This corresponds with what had already been described in the literature about the effects low literacy can have on people [32,33]. To the best of the knowledge of the researchers of the current research project though, no earlier studies have revealed the specific problems patients with low literacy experience with regard to completing health-related questionnaires. The problems low literacy people face cause them to be hard-to-reach as participants in research [34,35], especially when questionnaires are involved. This may be an explanation for the low percentage of low (health) literacy people being included in the evaluation studies of both the Dutch version of the PSC, described in **Chapter 2**, and the Dutch version of the TTSQ, described in **Chapter 4.1** and **4.2**, in comparison with the percentage of people with low (health) literacy in the Dutch population [36]. Despite all efforts the researchers put into developing recruitment strategies and choosing methodology in a way that would accommodate people with low (health) literacy, not many such people were reached. A lot of insight that was gained during the current research project in perspectives of low literacy people on the use of questionnaires, came from the information the ten designers

with low literacy gave during the design process of the TTSQ, which was described in **Chapter 3** of the thesis. These ten people had already formed a group as participants following a reading and writing course. This made them less hard-to-reach because they had already 'come out' as having low literacy when they decided to register for the course. They felt more confident acting as part of a group. And their teacher, who they already trusted, acted as an intermediary during the recruitment phase and stood by them during the design sessions. This helped these designers feel safe. Having a well-respected and trusted intermediary was also a success factor in the recruitment of low health literacy participants in the evaluation study of the Turkish TTSQ, which was described in **Chapter 4.3**. The researchers managed to include fifty percent participants with low health literacy within this study population. Once included, though, accommodating low literacy participants still proved to be challenging. Despite all efforts made by the researchers to inform potential participants thoroughly and make sure that participation was voluntary, it seemed that some participants had not really foreseen what they would get themselves into when they agreed to participate in the study. The majority of the participants seemed to have 'a lot on their plate'. Not only were they in low health but they also had social and financial problems, which made it hard for them to concentrate on the tasks given to them during the data collection process. Another complicating factor during data collection was the fact that participants were interviewed by a Dutch-speaking researcher, helped by an interpreter if necessary, while they had to complete a Turkish questionnaire. This bilingual setting made it even harder for participants to concentrate on their tasks. All of these complicating factors may have caused them not to be as positive about the use of the Turkish TTSQ in future health care as the participants in the evaluation of the Dutch version of the TTSQ were. Although problems with and solutions for recruitment of hard-to-reach participants are described, problems with and solutions for *conducting* research within these vulnerable populations are still hard to find in the literature. More research is necessary to gain insight into what exactly caused the problems the participants in the evaluation study of the Turkish version of the TTSQ encountered in both completing the questionnaire and participating in the study itself. Still, the results of the study confirmed the results of the evaluation studies of the Dutch version of the TTSQ that the current prototype does not fully solve the problems low (health) literacy persons have with completing

questionnaires. This shows how hard it still is to accommodate these vulnerable native and minority patient populations with inadequate health literacy in both research and clinical settings.

THE USE OF QUESTIONNAIRES IN CLINICAL PRACTICE

According to the definition of the U.S. Department of Health and Human Services, Food and Drug Administration, completing the TTSQ produces Patient-Reported Outcomes (PROs). A PRO is defined as any report of the status of a patient's health condition, behavior or experience with health care that comes directly from the patient without interpretation of the patient's response by a clinician or anyone else [37]. Researchers and policy makers have spent the last three decades promoting the routine use of Patient-Reported Outcome Measures (PROMs) in clinical practice [9,38]. They believe that it helps to evaluate the burden of disease and treatment from the patient's perspective [38], stimulate discussion of patient outcomes during consultations and increase patient satisfaction about provider-patient interactions [39]. This coincides with the increased demand for autonomy and self-determination of patients [40] and the ongoing effort that policymakers, researchers and health care professionals put into further development of shared decision-making and self-management in patients [41]. Furthermore, the use of PROMs clinically significantly reduces prevalence and severity of symptoms [39].

Researchers and policy makers use PROMs at an aggregate level for comparative effectiveness research [12], assessment of the performance of clinicians and organizations, public reporting and value-based payments [10]. They encourage routine application of PROMs by clinicians, believing aligning clinical practice and performance measurement will maximize the impact of PROMs on the quality of health care [9]. Among the implementation strategies that have been carried out in the past decade are the uptake of the use of PROMs into all guidelines for physical therapy practice, and health insurance companies making the use of PROMs obligatory or rewarding physical therapists financially for the use of PROMs [42]. Considering the results of this PhD thesis, which show how difficult it is for the majority of patients in a 'real life clinical setting' to complete questionnaires in a way which leads to valid results, one could ask oneself if all of this is justifiable.

RESEARCH CONTEXTS VERSUS REAL LIFE CLINICAL PRACTICE SETTINGS

Research may show benefits of using PROMs in clinical practice [38,39], but these results do not necessarily apply to all 'real life clinical settings', since people with low health literacy are generally overrepresented in patient populations but underrepresented in research populations [35]. Especially in research that involves the use of questionnaires, participants with insufficient reading and writing skills (which in the Netherlands is one in six persons of 16 years and older [43]) are either excluded intentionally by researchers or unintentionally as a result of low literacy patients choosing not to participate because they do not want to put themselves in such a demanding situation [35]. A systematic review of Valderas et al. [44] showed that clinicians are more dependent on the usability of questionnaires than researchers are, because researchers exclude participants who are not up to the task and they have the time and the means to create the optimal circumstances for participants to correctly complete the questionnaire(s) of interest. In addition, researchers have the time and the means to select the most appropriate questionnaires to meet their measurement goals and to deepen their knowledge of the questionnaires they use, which enables them to interpret the outcomes correctly and use them in a justifiable way to guide diagnostic and treatment decisions, treatment planning and/or treatment evaluation [44]. This is all much more difficult for clinical therapists who have very limited time and means to get all of this done within the complex and demanding context of clinical practice [45], in which an ever-growing amount of questionnaires are available for their use [46]. Results of research exploring the perspectives of patients on patient burden and added value of the use of PROMs in clinical practice are not all that positive [28-31], especially for patients with low health literacy [27]. Clinicians are less eager to incorporate the use of PROMs in their practice than researchers and policy makers are [44]. In fact, in a qualitative study on the use and usefulness of the most-used PROM in Dutch physical therapy practice, all participating physical therapists admitted that their main reason for using this PROM was to meet external obligations from health insurance companies and quality audits [42]. The results presented in **Chapter 2** and **4** of this current PhD thesis give some insight into why patients and clinicians lack enthusiasm when it comes to the use of PROMs in clinical practice. In **Chapter 2**, it is shown how difficult it is for patients

to independently complete the PSC [1], which is the most frequently used PROM in Dutch physical therapy practice [39], in a way that meets its purpose. This does not only apply to patients with low health literacy, but to physical therapy patients in general. Additionally, the results of **Chapter 4** show how difficult it is to adjust this questionnaire in a way that makes it possible for low literacy people to complete it without the help of anyone else and provide questions and answer options that can only be interpreted in one way, reducing the chances of creating bias. It is known that questionnaires are mostly drawn up by researchers and professionals who want to gather information and quantify the patient's condition on aspects that they are able to treat, while patients want to share information about the way their condition is affecting their lives [47]. All of this information combined raises the question to what extent using PROMs in 'real life clinical practice' really adds to bringing the undiluted patient perspective into the clinical decision-making process.

DEVELOPMENT OF TALKING TOUCHSCREENS SINCE 2003

5

In 2003 Elisabeth Hahn and David Cella were the first authors who described the necessity of developing a Talking Touchscreen (TT) for low literacy patients [15]. Within this key paper, they drew a very detailed and complete picture of the disadvantaged position of this vulnerable population when it comes to health and the ability to make effective use of health care. This description still applies to the situation of people with low (health) literacy in the Netherlands today [41,48,49]. Although the researchers and design team of the current project did not look at the design of previously-developed TTs and followed their own path during the development of the TTSQ, the first TT described by Hahn and Cella [15] shows many similarities with the prototype of the TTSQ.

Just like the TTSQ that was subject of the current thesis, the TT of Hahn and Cella [15] was developed on a portable touchscreen and one question per screen was shown. Instructions on the functionalities on the screens were given in the first screen. Different from the TTSQ, each question in the TT of Hahn and Cella was automatically read out loud and small picture icons of an ear appeared near each text element, in order for the respondents to be able to replay the sound of each element as many times as they wished to. Figure 5.2 shows sample screens for one question in English and in Spanish.

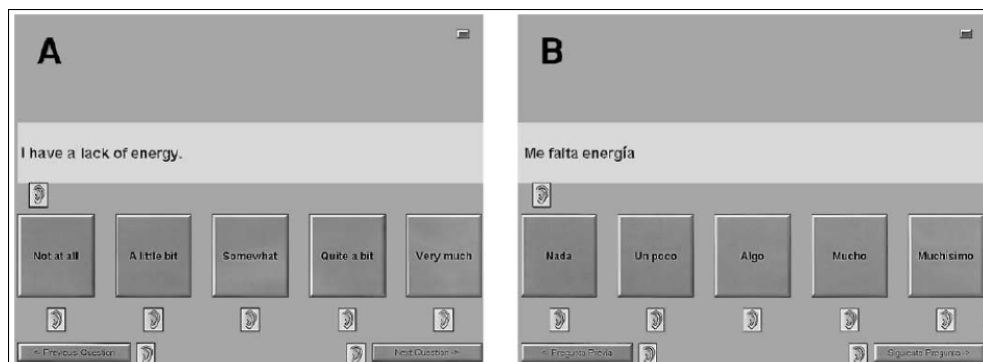


Figure 5.2. Examples of a screen of the first TT of Hahn and Cella in (A) English and (B) Spanish [15]

The layout and user interface of the TT questionnaires that Elisabeth Hahn and her team have developed since 2003 do not differ much from their first design [17-21]. In addition to the examples of screens in fig. 5.2, Hahn et al. published samples of an instruction screen (see fig. 5.3) and a more complicated question (see fig. 5.4) in articles that were published in 2004 and 2010 [17,19]. A demo of the most up-to-date version of their TT can be found on their website: www.healthlitt.org.

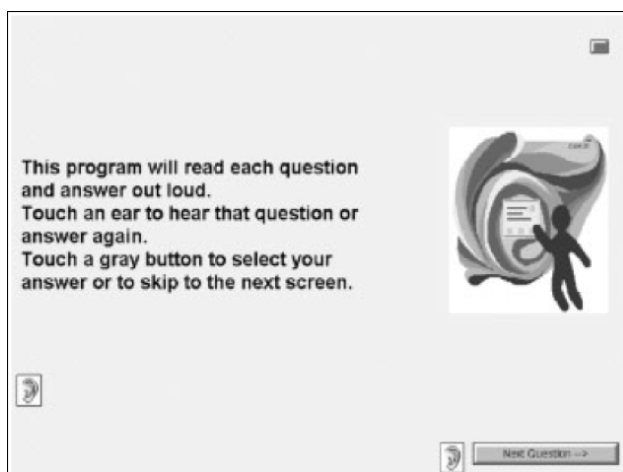


Figure 5.3 Example of a screen containing instructions on how to use the TT [17]

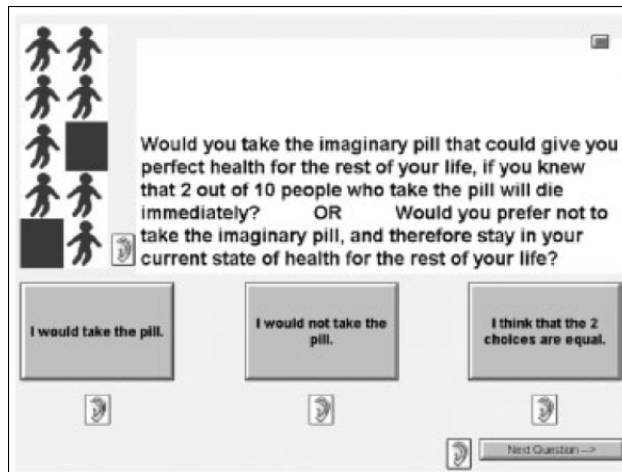


Figure 5.4 Example of a screen containing a complicated question [17,19]

5

No images of the TTs developed by Thornberry et al. [26], Hofmann et al. [23] and Paiva et al. [22] were published but they refer to Hahn et al. in their publications and their description of the design of their TT is very similar to the description given by Hahn and Cella [15].

The Smiling Touchscreen (ST) developed by Thumboo et al. [25] looked very different from the TT of Hahn et al., as can be seen in fig. 5.5 and it had more advanced features. Each question was shown on a separate screen, similar to the TT of Hahn and Cella [15], but in the ST a video clip of an interviewer reading the question out loud was added to the screen. Apart from multiple choice answer options, the tool of Thumboo et al. [25] contained answer options in the form of a Visual Analog Scale (score range: 0-100, 10-point interval).



Figure 5.5 Screenshot of the Smiling Touchscreen [22]

Vargas et al. published an article in 2010 in which they described their version of the TT [24]. Their design differed from the designs of Hahn et al. [15-21] in that questions were presented in the form of video clips which participants could replay as often as needed, and a stylus was used to enter responses on the touchscreen [24]. No images of the tool of Vargas et al. have been published but, according to its description, it seems to hold the middle between the design of Hahn and Cella (see fig 5.2, 5.3 and 5.4) [15, 17 and 19] and Thumboo et al. (see fig. 5.5) [25].

USABILITY OF TALKING TOUCHSCREENS

User-interface design

None of the earlier-developed TTs were designed in collaboration with members of the low (health) literacy target population [15-26]. The prototypes were tested by patients and, in some cases, the feedback provided by patients led to adjustment of the original design, like adding the Drag function and + and - buttons for fine adjustment of the answer on a VAS to the design of Thumboo et al. [25]. However, in a co-design approach [50], like the one that was taken by the researchers of the current project and described in **Chapter 3**, collaboration with future users was taken a step further. In the current project, ten persons with low literacy were part of the design team. They helped create the TTSQ from the very beginning. Various methods were used to enable these designers to deliver their input into the design. This

input has had a great impact on the design of the TTSQ and resulted in the guidelines for designing interactive questionnaires for persons with low literacy which are presented in **Chapter 3** of the current thesis. Because of the input of these designers, the screen of the TTSQ, for instance, contains as few functions and buttons as possible, and does not have a back function. Instructions and background information are only given in spoken, not in written, text. All pictures and illustrations shown on the screens are as concrete as possible, functional and relevant to the question that is being asked. Respondents are provided with regular overviews of given answers and a Stop function which gives them the command to stop completing the questionnaire at any time. Furthermore, the TTSQ contains answer options in the form of buttons with text, a body chart, pictures on which activities are shown, and a numeric rating scale. The numeric rating scale is colored from green for 'not severe' to red for 'severe' and contains absolute figures as opposed to an ongoing scale like, for instance, a Visual Analogue Scale. Everything in the design of the TTSQ is aimed at keeping the operation of the TTSQ simple, avoiding information overload and helping respondents to oversee their tasks, without feeling pressured into doing something they fear they cannot do. The screen samples of Hahn et al. in fig. 5.2, 5.3 and 5.4 [15;17;19] show a lot of buttons and answer options which contain text in a small font, instructions in written text accompanied by an illustration which is not functional or relevant in relation to the written text, and a screen which contains a complicated question, accompanied by a functional picture. One could argue about whether or not the images/pictures used in fig. 5.2, 5.3 and 5.4 are concrete enough for people with low literacy to help them understand the question better. Looking at the designer guidelines in **Chapter 3** of this thesis, the screens in fig. 5.2, 5.3 and 5.4 may not be the calm and clear images low literacy respondents are looking for. This may be even more true for the screen of Thumbou et al. in fig. 5.5 [25], which contains a lot of information and functions in various forms. Which kinds of screens, features or functions do and do not contribute to the ease of use of the various kinds of TTs is hard to say, though. The results of all earlier published studies on TTs [15-26] are difficult to compare with the usability results for the Dutch and Turkish versions of the TTSQ, presented in **Chapter 4.2** and **4.3** of this thesis, because of differences in methodologies used and study set-ups.

Comparable to the design process of the TTSQ in the current project, the content of the TT of Paiva et al. [22] was developed with input from patients and experts in oncology. Afterwards, the prototype was tested on comprehension and reliability. However, all of this was done using a paper-and-pencil version of the questionnaire. This means all patients that helped to develop and test the questionnaire were adequately literate or else they would not have been able to give the right input. Therefore psychometric properties of cancer-related questionnaires, like the one that was subject of the study of Paiva et al., established in adequately literate populations do not automatically apply to low literate populations. This may limit the generalizability of the results in the study of Paiva et al. [22].

Ease of use

The usability results of previously-published papers on TTs are hard to compare with the results published in the current thesis. The main reason for this is that respondents in all other studies were allowed to ask for the assistance of a researcher during completion of the questionnaire [15-26], while the participants in the two usability studies in this current thesis were not. The participants in the usability study on the Dutch TTSQ only were encouraged by the interviewer sometimes to "try again" if the touchscreen did not respond to their touch because they tapped too softly or pushed too hard on the screen. The participants in the study on the Turkish version of the TTSQ did not get any encouragement or support from the researchers at all. Some of the earlier published articles reported the percentages of participants who received help [16,17,20,22,25] and some gave some information about the amount of help that was received [17,20,22,25]. Three articles provide small bits of information on the characteristics of the participants that needed (the most) help with completion of the TTs. The information given indicates that low-skilled and inexperienced participants needed the most help [17,20,25]. This seems to align with the results on satisfaction reported in three TT evaluation studies [16,19,21] which show that, although overall satisfaction on the ease of use was high, satisfaction among lower-skilled or digitally-inexperienced participants was lower. The other studies did not specify the results on satisfaction by patient characteristics. Although it is difficult to compare the results of the earlier published TT studies with the results on usability in **Chapter 4.2** and **4.3** of the current thesis, they all seem to indicate that it is harder for less-skilled and

less-experienced patients to use a TT than it is for higher skilled and experienced participants.

Evaluating usability

In all earlier published articles on TTs [15-26] terms like 'usability', 'ease of use', 'usefulness', 'acceptability', 'practicality', 'user-friendliness' and 'feasibility' seem to be used as interchangeable terms and none of the authors have defined what they meant by these terms or how they measured them. All authors of those studies concluded that the TTs tested were easy to use for people with different levels of education, literacy or digital skills. These conclusions were based on study participants' level of satisfaction with the ease of use of the tool [15,18,19,22], on results on efficiency of the tool [23], or both [15,17,21,24-26]. Effectiveness was not, or in case of Vargas [24] and Thumboo et al. [25] very minimally, tested. It is known that the TT of Hofmann et al. has been tested on satisfaction, efficiency and effectiveness, as was recommended by Frokjaer et al. [51], because these authors refer to these tests in their article published in 2010 [23]. However, the exact methods and results of those pre-tests were never published. According to Frokjaer et al., it is important to evaluate and report all three aspects of usability at the same time because they consider effectiveness, efficiency and satisfaction as independent aspects of usability and state that it is risky to assume that there are correlations between these aspects [51]. The results presented in **Chapter 4.2** of this thesis confirm the necessity of combining all three aspects of usability, as all participants in the usability study of the Dutch TTSQ were extremely satisfied with the ease and efficiency with which they were able to use the TTSQ, while the results on effectiveness showed that it needed to be improved before it could be released. Based on the results of the study presented in **Chapter 4.2**, the authors purposed the Expectation Confirmation Theory [52] as a possible explanation for the extremely high satisfaction among the participants. According to the Expectation Confirmation Theory [52], the more their expectations are exceeded the more satisfied people are. From the perspective of this theory, the low self-efficacy towards being able to use the TTSQ participants had in the study presented in **Chapter 4.2** of this current thesis, in combination with the effort that was put into the design in order to make it easy to use, could have exceeded expectations among the participants. The results of a few earlier studies strengthens this hypothesis [17,19,21,26]. Yost et

al. reported that participants were *overwhelmingly* positive about the ease of use of the tested TT [21]. And Hahn et al. reported in 2004 that overall satisfaction was high and 75% of the participants reported that their expectations were exceeded, while at the same time 80% of the participants were dissatisfied with the efficiency with which they were able to complete the questionnaire [17]. Thornberry et al. reported that the more vulnerable and digitally-inexperienced participants were, the more they had enjoyed working with the TT [26]. All of these findings confirm the hypothesis that the Expectation Confirmation Theory [52] can be used as an explanation for the high satisfaction about the ease of use of TTs among participants in evaluation studies. And, just as in the study reported in **Chapter 4.3** of this thesis on the Turkish version of the TTSQ, Thornberry et al. found that when participants 'had too much on their plate' because of health or social problems, they were less satisfied with the ease of use of the TT [26]. The results in the study presented in **Chapter 4.3** of this thesis show that these participants seem to be less able to concentrate on their tasks during the data collection phase. Even though there are no results on the effectiveness with which the earlier described TTs could be completed, the results for satisfaction seem to create a similar picture as do the results for the usability of the TTSQ.

VALIDITY OF TALKING TOUCHSCREENS

A qualitative approach in validity testing

Since not much is known about the validity of questionnaires in populations with low health literacy, the researchers of the study described in **Chapter 4.1** were interested in possible differences between the problems occurring during the response processes of participants with lower and higher health literacy. People with low health literacy are usually either excluded intentionally by researchers selecting only people with proficient reading and writing skills, or unintentionally, because these people refuse to participate in such studies because they do not wish to put themselves in such demanding situations [15,35]. Therefore, the researchers conducted the qualitative TSTI method [4] which resulted in a detailed view and deep understanding of the problems that arose during the response processes of all participants completing the TTSQ. A direct study of the question-and-answer process gave the researchers the opportunity to identify problematic items in the TTSQ and at the

same time get a detailed insight in what caused these problems. These insights are useful input for further development of the TTSQ. Another benefit of choosing a qualitative approach was that it did not demand any reading or writing skills from the participants. In the eyes of the researchers, this increased the chances of being able to include people with low (health) literacy in the study. At the very least, it would make people who had problems with reading and writing *able* to participate. Eventually, the researchers succeeded in including six less-educated participants (max. primary school), of whom two had low basic reading and writing skills, into their study population of 24 people. The results of the study showed that no educational group in this research population stood out from the rest in the kind or number of problems that arose. All respondents recognized themselves in the outcomes of the questionnaire. The use of plain language and ICT within the TTSQ, however, had both positive and negative effects on the response processes. This is a valuable insight, which may not have been derived from more commonly conducted quantitative validity testing approaches, since these methods help researcher to detect problems, but do not provide a detailed view and deep understanding of the nature and causes of these problems.

Validity testing methods used by other researchers

A few researchers in previously-published studies on TTs have also assessed validity aspects of their tool. Two different approaches may be distinguished.

In the study of Paiva et al. [22], 323 participants completed a paper-and-pencil version of the newly-developed questionnaire that was the subject of the study and would later on be digitalized for the TT. Fifty percent of this study population had less than 8 years of formal schooling. Five percent of the total population was illiterate. How illiteracy was determined was not reported in the article. Whether participants who had problems with reading and writing managed to complete the questionnaire, and if so, how they managed to do this, was not reported in the article either. The same article, however, reported that in another part of the study, in which the paper-and-pencil version of the questionnaire of subject was compared with its digital equivalent, 28% (15/54) of the participants had not been able to complete the paper-and-pencil version. Nine participants who did not manage to complete the questionnaire had inadequate, three had marginal and three had adequate health literacy. To determine

the validity of the questionnaire, the domains of the questionnaire were compared with two corresponding paper-and-pencil-based questionnaires that were seen as 'gold standards' for the subjects of interest. The same question rises about whether or not all participants were able to autonomously complete these 'gold standard' questionnaires. If participants were assisted by a researcher, this may have created interviewer bias [53]. Another question that should be asked in this situation is whether or not the questionnaires that have been used as 'gold standards' can be seen as such for the target population of the TT. Paiva et al. reported that the 'gold standards' were previously validated [22]. The research population of the validation studies of one 'gold standard' was comparable on educational level to the study population of Paiva et al. [54]. The characteristics of the research population of the other 'gold standard' were not described in terms of educational level [55]. In both validation studies of the 'gold standards', nothing was reported about the reading and writing skills of the participants. People who had difficulties reading and writing were not actively excluded, but on the other hand no specific efforts were described that were made to include them either [54,55]. Therefore it is unknown whether or not participants with low (health) literacy were part of the study populations in the validation studies of the 'gold standards'. This makes it uncertain whether or not the results of these studies are transferable to the target population of the TT of Paiva et al. Furthermore, only the validity of the paper-and-pencil version of the newly-developed questionnaire of Paiva et al. [22] was tested, and not that of the digital version. Looking at the results of the study presented in **Chapter 4.1**, it is necessary to test the validity of the digital version, because adding ICT to a questionnaire could potentially influence its validity.

STRENGTHS AND LIMITATIONS

Strengths

The research project described within this thesis was a typical practice-based research project [56]. It was set up and carried out with the help of eight physical therapists, working in deprived areas of Utrecht, Netherlands. The problems these therapists experienced with using PROMs within their patient populations was the direct reason for setting up this research project. Furthermore, the collaboration with ten designers with low literacy during the whole course of the

design process resulted in new insights in perspectives of people with low literacy regarding the use of questionnaires. It resulted in knowledge about technical, as well as social and psychological, aspects of completing questionnaires that need to be taken into account when designing for low literacy people. This knowledge was used in the design of the TTSQ and also resulted in published guidelines for designing interactive questionnaires for persons with low literacy.

The researchers of the current research project have been able to include some of most vulnerable members of their target populations in their studies. The qualitative approach which has been taken has enabled the researchers to reflect critically and deeply on the usability of the TTSQ for these vulnerable members of the target population. The Three-Step-Test-Interview [4] approach proved to be a very useful method to get a deep understanding of the problems and causes of the problems which were encountered by participants during their completion process. All studies together produced knowledge of difficulties people with low (health) literacy face in daily life, health care and, more specifically, in completing (health-related) questionnaires and their participation in research projects.

5

Limitations

The co-design strategy conducted in the current research project has not yet led to a tool that is user-friendly and creates valid data for physical therapy patients with low (health) literacy. The results presented in the current thesis offer enough starting points for further development of the TTSQ, but future research will need to prove whether or not adjustments will lead to the desired results. An important lesson learned, though, is that the development of this tool is very time- and labor-intensive. This is due to the qualitative methods that need to be applied in order for vulnerable potential future users of the tool to be able to participate in the studies and the effort that needs to be put into the recruitment of these hard-to-reach participants. Therefore, it will be challenging to find the time and the means to realize such a follow-up project. Because of the lengthy and costly development procedures, investing in the development of tools like the TTSQ will not be cost-effective for commercial parties. A possible follow-up project will be dependent on community funds.

RECOMMENDATIONS FOR FURTHER AND FUTURE DEVELOPMENT OF TALKING TOUCHSCREENS FOR USE IN CLINICAL PRACTICE TO SUPPORT PATIENTS WITH LOW HL

Recommendations for clinical practice

The findings on the difficulties participants had with the use of the PSC, described in **Chapter 2** of this thesis, were in accordance with the findings of four other studies on ease of use and respondent burden of regularly used PROMs [28-31]. In all four of these studies, difficulties with the interpretation of questions and response categories were found, due to different perspectives between patients and the developers of the questionnaires. In none of these studies was the level of (health) literacy of the respondents taken into account, which may mean these outcomes are still too positive and not generalizable to a 'real life patient population'. Based on the knowledge the current PhD study adds to already existing knowledge about problems encountered by patients and clinicians in using PROMs, the worth and legitimacy of routine use in clinical practice of PROMs in their current state may need to be reconsidered.

Clinicians should demand from researchers and developers that they engage representatives of the full variety of members of their target populations in the development and evaluation process of PROMs. This also means that clinicians and developers of practical guidelines should take into account whether or not researchers have considered the needs of patients with low (health) literacy in choosing recruitment, development and evaluation strategies during the development and evaluation process of a PROM. An important step in stimulating questionnaire developers to take ease of use, face and content validity of PROMs into account has already been taken by incorporating assessment of these psychometric criteria into the COSMIN checklist [46]. If a PROM is not tested in a research population that is representative for a 'real life patient population', clinicians are right to be very reluctant in using it in clinical practice. The chances are that such a PROM may not add to the quality of valid information exchange, therefore not leading to better provider-patient interaction. In fact, due to factors earlier described in this general discussion, it may diminish the quality of communication and lead to unwanted and dysfunctional situations. If clinicians get the impression that patients are not willing or able to autonomously complete a questionnaire, they

should stop asking them to do so.

If the specific goal of a physical therapist is not measurement of PROs but to engage patients in goal setting, using traditional PROMs may not be the most effective way to do this. Instead of using the PSC, it would be preferable to choose the 'Patient-Specific Goal-setting method' (PSG). This method was developed as a substitution for the PSC and specifically aimed at physical therapists enabling their patients to participate in the goal-setting process. Different from the PSC, which needed to be completed autonomously by the patient, the PSG is a six-step method embedded across the physiotherapy process, in which patients are stimulated by a physical therapist, who was trained specifically for this purpose, to participate in the goal-setting process [42].

Recommendations for future research

It is of great importance that researchers keep striving for further development of user-friendly, valid and reliable TT questionnaires that can be used in 'real life patient populations', including native *and* minority patients with low health literacy. This will greatly benefit the generalizability of PROMs in research and may add to the feasibility of implementing routine PRO measurement in clinical practice. It will empower and emancipate vulnerable patients by enabling them to give their undiluted input to research and clinical practice. Being able to do this autonomously will reduce staff burden and costs and potential interviewer bias. It may also reduce feelings of embarrassment and make people with low literacy feel safer and more worthy within both research and clinical settings, because they will be able to use the same tools as do people with greater health literacy. Results of the study of Hahn et al. already indicate that assumptions being made based on results of paper-and-pencil health-related quality of life questionnaires about the relationships between health literacy and health-related quality of life may be influenced by measurement bias [18]. Therefore, developing measurement tools that suit the needs and abilities of the great number of people with low health literacy is of utmost importance.

In order for TTs to contribute to the quality of health care and active input of patients into the patient-provider interactions on a wide scale, a substantial amount of commonly-used questionnaires like the PSC need to be tested for usability in 'real life patient populations'

and, if necessary, adapted and put into TTs. These TT questionnaires should be made available in different language versions, such as English, French, Spanish, Arabic and other languages which are commonly used by minority populations of a specific country. It may be interesting to add information about health, illness and treatment to the tools, so TTs can be turned into 'health information kiosks'. Kiosks are free-standing units containing computers that provide users with information services such as health education programs [57]. The results of evaluation of the usefulness of such kiosks is promising but, to the best of our knowledge, such kiosks have not yet been developed to be usable by users with low health literacy. Research is needed to investigate if it is possible to make those kiosks user-friendly and effective in gathering PROs and giving health information to 'real life patient populations', including patients with low functional health literacy. More research is also needed to get insights in other possible platforms, as well as funds that will help develop and implement the use of TTs in research and clinical practice.

Developing TTs has proven to be a very labor- and time-consuming, and therefore expensive, process. On the other hand, having usable, valid and reliable TTs may well save a lot of time and money in the future. Physical therapists that participated in this research project told the researchers that assisting vulnerable patients in completing PROs could take them up to one and a half hours of treatment time at the beginning *and* the end of a treatment process while, at the same time, they feared the risk of interviewer bias [53]. It is also known that low health literacy in itself influences provider-patient interaction negatively [8] which leads to suboptimal health outcomes. Therefore, research needs to be done to investigate whether TTs can lower staff burden and costs and increase health outcomes by means of increasing the quality of provider-patient interaction, through enabling vulnerable patients to autonomously complete questionnaires which provide valid and reliable PROs. Adding safe software to TTs which transport outcomes safely to electronic patient files, without human interference, would reduce staff burden and costs even more. If research shows that the use of TTs reduces costs and increases quality of care, investing in the development of TTs containing large amounts of questionnaires in various language versions may become interesting to health insurance companies and health care providers.

During all future evaluation studies, researchers should avoid giving assistance and encouragements to participants completing a TT questionnaire in order to avoid interviewer bias, increase transparency of data collection and do justice to the goal of supporting patients in taking on an active mutual-partnered role in provider-patient interaction. Furthermore, the quality of usability studies can be increased by incorporating technology for eye tracking and monitoring of use of buttons and functions, as well as recording completion time of sections of a questionnaire and the questionnaire as a whole, into TTs. The TSTI method [4] proved to be a very useful and thorough method to test usability as well as validity of TT questionnaires in research populations that include participants with low functional health literacy. When TSTI research into a TT questionnaire shows satisfactory outcomes on validity, a next step in the validation process can be taken by applying quantitative research using Item Response Theory [58] to create representative data, without the need for participants to fill out an additional questionnaire as a 'gold standard'.

The current research project has confirmed what has been earlier described about how hard it is to recruit and include hard-to-reach patient populations [35]. The researchers of the current project have been able to include vulnerable members of the target populations in all of the studies presented in this thesis. They were able to do so by carefully choosing suitable data collection methods and using physical therapists as intermediaries for recruitment of eligible patients and training them in recognizing and communicating with people with low functional health literacy. Training physical therapists in recognizing low functional health literacy in people was necessary because, at the beginning of the current research project in 2010, apart from the Dutch version of the Set of Brief Screening Questions [59], Dutch versions of Health Literacy Assessment tools were not available and the awareness of clinicians about the meaning and ramifications of low functional health literacy was not yet widespread. A lot has changed in these aspects in the past eight years. Physiotherapists, not least the ones that participated within this research project, are very much aware that there are people with low functional health literacy among their patient populations. In theory, it should be easier to identify them because of the increasing availability of feasible Dutch versions of good quality functional health literacy assessment tools such as the Dutch versions of the Short Assessment of Health

Literacy (SAHL-D) [60] and the Newest Vital Sign (NVS-D) [61]. In the current project, though, the researchers were forced to drop their ambition to perform a last study on the impact the TTSQ may have on provider-patient interaction with patients with low health literacy. In spite of numerous adjustments in their recruitment strategy, the researchers only managed to include five such patients (measured with the Dutch version of SAHL-D) [60] in 1.5 years of recruitment in a physical therapy practice which was located in a deprived area of Utrecht, Netherlands. This shows how hard to reach this population really is. Among a variety of reasons that make it hard to reach this population may well be the fact that persons with low functional health literacy tend to avoid challenging situations, like participating in research, especially when they know that their (health) literacy skills will be tested. Using TT technology for health literacy assessment is a promising development which may help solve this problem, because people seem to feel less reluctant to answer questions and be tested on subjects they feel ashamed about in the absence of an interviewer [18,26]. The shame of having low literacy, being poorly educated and having trouble communicating in Dutch did not seem to play a significant role in the recruitment of Turkish participants. These participants openly discussed their limitations in these areas. One of the researchers in the current project functioned as a Turkish intermediary. His role was described thoroughly in **Chapter 4.3** of this thesis. Because of this strategy, the researchers managed to include the most vulnerable members of the target population. This led to other problems, though, because, although very carefully chosen, the research methodology used was too burdensome and challenging for some of the study participants. Various researchers have shared their experiences with recruiting, including and working with hard-to-reach populations in social and medical research [35]. Researchers should keep doing this in order to help each other strive for research results that are transferable to and representative of 'real life patient populations'. However, it is hard to give full insight in successful and unsuccessful (elements in) recruitment strategies and research methods in papers that primarily revolve around *results* of research. Therefore, it would be interesting to develop research projects with the primary goal of investigating what strategies, techniques and methods increase or decrease participation of members of hard-to-reach populations in research.

CONCLUSIONS

The aim of the research project that was described within this thesis was to adapt a screening questionnaire and develop a tool which would help Dutch and Turkish physical therapy patients with inadequate HL to be more capable of taking an active part in the decision-making process within the diagnostic phase of physical therapy treatment in the Netherlands.

The current prototype of the TTSQ does not yet fully solve the problems native and minority patients with low HL have with completing the adapted questionnaire. Looking at the results of all studies presented in the current thesis, the prototype of the TTSQ needs to be improved in both usability and validity aspects. Much work needs to be done to further develop the TTSQ and test it on psychometric properties. Big challenges in future development and testing the TTSQ are the recruitment of vulnerable members of the hard-to-reach native and minority target populations and finding research methods that suit the abilities and needs of these participants. The TTSQ, as well as its development process, needs to be designed in a way that puts persons with low HL at ease and enables them to participate fully autonomously. The results presented in the current thesis offer starting points for further development of the TTSQ, but future research will need to prove whether or not adjustments will lead to the desired results. It will be a very challenging, labor- and time-consuming process to create a TTSQ which has good psychometric properties for use in a 'real life patient population', including native and minority patients with low HL. On the other hand, having a usable, valid and reliable TTSQ may well save a lot of time and money in both research and clinical practice in the future. If future research shows that the use of the TTSQ reduces costs and increases quality of care, investing in the development of a TTSQ which contains large amounts of questionnaires in various language versions may become interesting to health insurance companies and other investors. A structure in which community funds help finance the development and implementation process of the TTSQ, comparable to the way the projects of Hahn et al. are financed [15-21], will be indispensable in making further development of the TTSQ possible.

Based on the knowledge the current PhD thesis adds to already existing

knowledge about problems encountered by patients and clinicians in using PROMs, the worth and legitimacy of routine use of PROMs in their current state in clinical practice may need to be reconsidered. Clinicians should demand from researchers and developers that they engage representatives of the full variety of members of their target populations in the development and evaluation process of PROMs. This also means that clinicians and developers of practical guidelines should take into account whether or not researchers have considered the needs of patients with low HL in choosing recruitment, development and evaluation strategies during the development and evaluation process of a PROM. If a PROM is not tested in a research population that is representative of a 'real life patient population', clinicians should be very reluctant in using it in clinical practice. The chances are that such a PROM may not add to the quality of valid information exchange, not leading to better provider-patient interaction. In fact, it may diminish the quality of communication and lead to unwanted and dysfunctional situations. If clinicians get the impression that patients are not willing or able to autonomously complete a questionnaire, they should stop asking them to do so. If the specific goal of a physical therapist is not measurement of PROs but engaging patients in goal-setting, using traditional PROMs may not be the most effective way to do this.

It is of great importance that researchers keep striving for further development of user-friendly, valid and reliable questionnaires that can be used in research populations that represent 'real life patient populations' including native *and* minority patients with low HL. This will greatly benefit the generalizability and validity of PROMs in research.

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CHAPTER 6

Explanation of the relative contribution
of the co-authors to the chapters

Summary

Samenvatting

Dankwoord

EXPLANATION OF THE RELATIVE CONTRIBUTION OF THE CO-AUTHORS TO THE CHAPTERS

Chapter 2

Welbie M, Wittink H, Westerman M.J, Devillé WLJM. Completing the Patient Specific-Complaint Questionnaire in physical therapy practice is problematic for high and low literate patients: a qualitative study. *Int J Pers Cent Med*. 2016;6(1): - doi: 10.5750/ijpcmv6i1.566

Welbie, Wittink and Devillé designed the study. Welbie M collected and analyzed the data. Wittink and Westerman peer debriefed the data analysis. Welbie wrote the first draft of the manuscript. Wittink, Westerman and Devillé contributed to the writing of the manuscript.

Chapter 3

Cremers AHM, Welbie M, Kranenborg K, Wittink H. Deriving guidelines for designing interactive questionnaires for low literate persons; development of a health assessment questionnaire. *Univ Access Inf Soc* 2017;16(1):161-72 doi: 10.1007/s10209-015-0431-2

Welbie, Cremers and Wittink designed the study. Welbie, Cremers and Kranenborg collected the data. Welbie and Cremers analyzed the data. Cremers and Welbie wrote the first draft of the manuscript. Wittink and Kranenborg contributed to the writing of the manuscript.

Chapter 4.1

Welbie M, Wittink H, Westerman MJ, Topper I, Snoei J, Devillé WLJM. Using plain language and adding communication technology to an existing health related questionnaire to help generate accurate information: qualitative study. *J Med Internet Res*. 2018;20(4):e14 doi: 10.2196/jmir.7940

Welbie, Wittink and Devillé designed the study. Topper and Snoei collected the data. Welbie analyzed the data. Wittink and Westerman peer debriefed the data analysis. Welbie wrote the first draft of the manuscript. Wittink, Westerman and Devillé contributed to the writing of the manuscript.

Chapter 4.2

Welbie M, Wittink H, Westerman MJ, Topper I, Snoei J, Devillé WLJM. A Mobile Patient Reported Outcome Measure (PROM) App for Physical Therapy Patients: Usability Assessment of the Dutch Talking Touch Screen Questionnaire. JMIR Form Res (forthcoming) doi:10.2196/11617

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Chapter 4.3

Welbie M, Wittink H, Bozkurt S, Coban T, Devillé WLJM. Usability of the Turkish translation of the Dutch Talking Touch Screen Questionnaire for physical therapy patients with a Turkish background; qualitative study. JMIR Form Res doi: 10.2196/preprints.14189

Welbie, Wittink and Devillé designed the study. Welbie and Bozkurt collected the data. Coban checked the Dutch translation of the Turkish data. Welbie analyzed the data. Bozkurt and Wittink peer debriefed the data analysis. Welbie wrote the first draft of the manuscript. Wittink and Devillé contributed to the writing of the manuscript.

THE DUTCH TALKING TOUCH SCREEN QUESTIONNAIRE

Supporting patients with diverse levels of health literacy in taking an active role during the diagnostic phase of physical therapy treatment

SUMMARY

Chapter 1 describes the introduction of this thesis. Over the last decades, the traditional paternalistic approach in health care is increasingly developing towards a patient-centered care (PCC) approach. Patients are expected to take on an active participating role. However, not all patients are able to take advantage of the positive effects of PCC. PCC demands of patients participation as an active partner, and information exchange is key to active patient participation. Inadequate health literacy (HL) is an important limiting factor in the ability of patients to take on an active role and exchange information with their health care provider effectively. Within the Dutch population, thirty-six percent have inadequate health literacy. According to the conceptual model of Paasche-Orlow and Wolf, inadequate health literacy causing problems in provider-patient interactions is one of the pathways through which health outcomes are influenced negatively. Health literacy itself is, amongst other factors, influenced by ethnic background, socio-economic factors, language proficiency and age. Finding a way to support patients with low HL to provide accurate and relevant information in a way that is comprehensible to their health care provider will improve provider-patient interaction. According to the conceptual model of Paasche-Orlow and Wolf, this will have a positive effect on health outcomes. A provenly effective approach to improvement of provider-patient interaction and health outcomes is the use of health-related questionnaires. Using traditional paper-based questionnaires is not likely to contribute positively to the situation of patients with low HL though, because low HL is strongly associated with low literacy. Therefore, one can assume that in patient populations with low health literacy the use of questionnaires will not contribute to provider-patient interaction and could even complicate the situation further. However, earlier research has shown that the use of a Talking Touchscreen (TT) increases the ability of low literacy patients to complete health-related questionnaires, even if they have limited or no computer skills. In order to avoid increasing health inequality between native and minority groups, researchers in earlier

publications on TTs emphasize the importance of creating different language versions of TTs in order to accommodate minority as well as native populations. The aim of the research project described within this thesis was to adapt the most frequently-used questionnaire in Dutch physical therapy practice and add TT technology to it. A Dutch and Turkish version of the tool was developed, since Turkish people form the biggest minority population in the Netherlands. Because it is not ethical nor practical to differentiate in levels of HL of patients in clinical practice, the tools were tested in populations of patients with diverse HL levels.

The first objective within this research project was to assess which problems physical therapy patients with diverse levels of HL and Dutch and Turkish backgrounds encountered during completion of the Patient-Specific Complaint questionnaire (PSC). The PSC was taken as a starting point for the development of the tool that was developed during this research project, which was called the Talking Touch Screen Questionnaire (TTSQ). The content of the PSC fitted the goal of helping patients to provide relevant information regarding their health problems to their physical therapist. It is aimed at making patients select their main limitations in functioning and formulate their own specific treatment goals. To assess which problems physical therapy patients encountered during completion of the PSC, cognitive interviews using probing techniques with 25 Dutch and 25 Turkish physical therapy patients with diverse levels of health literacy were conducted after they completed the Dutch PSC. The results of this study, which were described in **Chapter 2**, showed that all respondents, except for one, experienced problems completing the questionnaire. Most problems were related to comprehension of the instructions and questions, and this led 24 respondents, most of whom had low health literacy, to give invalid answers.

The results of the study described in **Chapter 2** led to the second objective of the research project which was the development of a working prototype of the Dutch TTSQ. This was described in **Chapter 3**. A co-design method was applied by involving ten low literacy persons in the design team from the start of the development process. User involvement was organized through two focus group sessions (analysis phase), two user walkthroughs (design phase), and a usability test (implementation) with a new group of low literacy persons. The design

process resulted in a digital application on the original iPad 1 with a 9.7-inch screen. A tablet computer was found to be the most suitable device to meet the needs of low literacy people since it has the capabilities of a computer, but it does not look like one and operating it does not require reading or writing skills. Questions on pain location and pain intensity were added to the original questions of the PSC, because users were primarily interested in reporting their complaints, not their activity limitations. Visual (videos and photos) and auditory (speech technology) support was added to enable participants to see and hear the questions which were shown on separate screens. Response items could be selected by tapping on the touch screen and plain language was used in all spoken and written texts within the TTSQ. The results of this study showed that, apart from the more 'technical' support, it is important to take the social and psychological aspects of completing questionnaires into account in designing for people with low literacy. Based on the lessons learned, guidelines for designing interactive questionnaires for low literacy persons were given within **Chapter 3**.

The last objective was to test whether the newly-developed Dutch TTSQ generated accurate information on symptoms, limitations and treatment goals of patients with diverse levels of HL in a physical therapy context and to test and compare the usability of the Dutch TTSQ and its Turkish translation. The Three-Step-Test-Interview method of Hak and van der Veer, containing both think-aloud and probing techniques, was used to get insight into the way 24 Dutch and 11 Turkish physical therapy patients with varying levels of health literacy were able to operate the TTSQ and how their answers came about. In **Chapter 4.1**, the accurateness of the information gathered through the Dutch version of the TTSQ in a population of physical therapy patients with different levels of health literacy and a Dutch background were evaluated. The results of this study show that the use of plain language and information and communication technology (ICT) had a positive effect on the comprehensibility of the Dutch version of the TTSQ. However, it also had some negative effects on the other four aspects of the response process: interpretation, retrieval, judgment, and response selection. Due to the plain language used, some questions missed detail, which made them multi-interpretable. Multi-interpretation was also problematic in the use of pictures as answer options for limitations in daily activities. Furthermore,

showing questions and answer categories in separate screens without a back function caused respondents to lose an overview of the whole questionnaire. This made it harder for them to decide whether or not they should select an answer or instead go on to following screens in the hope that these would contain more suitable answers. On the other hand, being provided with specific answer options made some respondents fail to actively search their memories and retrieve information about situations in which they were limited because of their health problem. The problems within the response processes led to invalid and incomplete results in 20 of the 24 cases. The participants did not notice the incorrectness and incompleteness of their answers, witnessing the fact that all participants reported they recognized themselves in the overall outcomes. No educational group in this research population stood out from the rest in the kind or number of problems that arose. **Chapter 4.2** evaluates the usability of the Dutch version of the TTSQ in a population of physical therapy patients with diverse levels of health literacy and a Dutch background. The results of this usability study show that all 24 Dutch participants were very satisfied with the ease of use and efficiency with which they were able to operate the questionnaire. The ease of use exceeded the expectations of the participants. However, the data on effectiveness showed 13 different kinds of problems occurring during operation of the questionnaire. According to the severity rating system of Nielsen & Loranger, nine of these problems were not likely to influence future usage of the tool substantially, but four problems needed to be addressed before the Dutch version of the TTSQ could be released. The less educated and less experienced participants were in using mobile technology, the more problems they encountered. **Chapter 4.3** describes the evaluation of the usability of the Turkish version of the TTSQ in a population of physical therapy patients with different levels of health literacy and a Turkish background living in the Netherlands. The results of this study confirm that participants with lower education and less experience in using mobile technology are less able to operate the TTSQ effectively. Most of the 11 Turkish participants, who were in general lower educated and less health literate than participants in the usability study of the Dutch version of the TTSQ, were not particularly satisfied or dissatisfied about the overall ease of use of the Turkish TTSQ. Two Turkish participants, who had no prior experience using mobile technology, felt that, regardless of what kind of improvements might be made, it would just be too difficult for them to learn to work

with the tool. Seventeen different kinds of problems were found, of which three needed to be addressed during future development of the tool based on their Nielsen and Loranger severity score. Because the research team had managed to recruit very vulnerable participants in terms of educational level, health literacy level, experience with using mobile technology, health and social status, the results of this study gave good insight in how hard it is for this group, not only to handle technology that is new to them, but to participate in a research project in the first place.

In **Chapter 5**, the results of the studies described in this thesis were put into a broader perspective by reflecting on the use of questionnaires in clinical practice in general and comparing both the methods used and results found within this thesis to those of other studies on similar tools. Finally, recommendations for clinical practice and future research were provided. In summary, the current prototype of the TTSQ does not yet fully solve the problems native and minority patients with low (health) literacy have with completing the adapted questionnaire. It needs to be improved in both usability and validity aspects. Much work needs to be done to further develop the TTSQ and test it on psychometric properties. Big challenges in future development and testing the TTSQ are the recruitment of vulnerable members of the hard-to-reach native and minority target populations and finding research methods that suit the abilities and needs of these participants. This is expected to be a very challenging, labor- and time-consuming process. On the other hand, having a usable, valid and reliable TTSQ may well save a lot of time and money in both research and clinical practice in the future. If future research shows that the use of the TTSQ reduces costs and increases quality of care, investing in the development of a TTSQ which contains large numbers of questionnaires in various language versions may become interesting to health insurance companies and other investors.

The worth and legitimacy of routine use of health-related questionnaires in their current state in clinical practice may need to be reconsidered. Clinicians should demand from researchers and developers that they engage representatives of the full variety of members of their target populations in the development and evaluation process of patient-reported measures. If a questionnaire is not tested in a research population that is representative for a 'real life patient population',

clinicians should be very reluctant to use it in clinical practice. The chances are that such a questionnaire will not add to the quality of valid information exchange, not leading to better provider-patient interaction. In fact, it may diminish the quality of communication and lead to unwanted and dysfunctional situations.

It is of great importance that researchers keep striving for further development of user-friendly, valid and reliable questionnaires that can be used in research populations that represent 'real life patient populations', including native *and* minority patients with low health literacy. This will greatly benefit the generalizability and validity of patient-reported outcomes in research.

DE NEDERLANDSE TALKING TOUCH SCREEN VRAGENLIJST

Het ondersteunen van patiënten met verschillende niveaus van gezondheidsvaardigheden bij het aannemen van een actieve rol tijdens de diagnostische fase in de fysiotherapeutische behandeling

SAMENVATTING

In **Hoofdstuk 1** is de inleiding beschreven van dit proefschrift. In de laatste decennia heeft de paternalistische benadering binnen de gezondheidszorg zich in toenemende mate ontwikkeld richting een patiënt gerichte benadering. Van patiënten wordt steeds meer verwacht dat zij een actieve participerende houding aannemen. Niet alle patiënten zijn echter in staat om hun voordeel te doen met de positieve effecten die een patiëntgerichte aanpak kan hebben, omdat patiëntgericht werken van de patiënt vraagt om zich als een actieve partner op te stellen. Kwalitatief goede informatie uitwisseling tussen patiënt en zorgverlener is daarbij van groot belang. Beperkte gezondheidsvaardigheden zijn een belangrijke belemmerende factor voor patiënten bij het aannemen van actieve houding en het effectief uitwisselen van informatie met hun zorgverlener. Zesendertig procent van de Nederlandse populatie is beperkt gezondheidsvaardig. Volgens het conceptuele model van Paasche-Orlow en Wolf hebben beperkte gezondheidsvaardigheden een negatieve invloed op de zorgverlener-patiënt interactie. Hierdoor hebben zij indirect een negatieve invloed op de effectiviteit van zorg. Het hebben van beperkte gezondheidsvaardigheden zelf wordt veroorzaakt door, onder andere, etnische achtergrond, sociaal-economische factoren, taalvaardigheid en leeftijd. Het vinden van een manier om patiënten te ondersteunen bij het verstrekken van accurate en relevante informatie die begrijpelijk is voor de zorgverlener zal de zorgverlener-patiënt interactie ten goede komen. Volgens het conceptuele model van Paasche-Orlow en Wolf zal dit een positieve bijdrage leveren aan de effectiviteit van zorg. Het is bewezen dat het gebruik van gezondheid gerelateerde zelfrapportage meetinstrumenten (veelal vragenlijsten) de zorgverlener-patiënt interactie en effectiviteit van zorg ten goede komt. Het is echter niet aannemelijk dat traditionele papieren vragenlijsten een positieve bijdrage leveren aan de situatie van patiënten met beperkte gezondheidsvaardigheden, omdat beperkte gezondheidsvaardigheid sterk gerelateerd is aan laaggeletterdheid.

Hierdoor kan aangenomen worden dat in beperkt gezondheidsvaardige patiëntpopulaties het gebruik van vragenlijsten niet zal bijdragen aan de zorgverlener-patiënt interactie en mogelijk de situatie verslechtert. Uit eerdere onderzoeken blijkt echter dat het gebruik van een Talking Touchscreen (TT) laaggeletterde patiënten in staat stelt om gezondheid gerelateerde vragenlijsten in te vullen. Zelfs als zij weinig of geen computervaardigheden hebben. Om te voorkomen dat het verschil in gezondheid tussen autochtone en migranten populaties toeneemt, wordt in de literatuur benadrukt dat het belangrijk is om verschillende taalversies van TTs te creëren. Zo kunnen zowel autochtone als migranten populaties worden bediend. Het doel van het in deze thesis beschreven onderzoeksproject was om de meest gebruikte vragenlijst in de Nederlandse fysiotherapie aan te passen en er TT technologie aan toe te voegen. Van de tool werd zowel een Nederlandse als Turkse versie ontwikkeld, omdat Turkse mensen de grootste minderheidsgroep in Nederland vormen. Omdat het niet ethisch en ook niet praktisch is om in de klinische praktijk onderscheid te maken tussen patiënten op basis van hun gezondheidsvaardigheidsniveau zijn de tools getest in populaties met patiënten met verschillende gezondheidsvaardigheidsniveaus.

De eerste doelstelling was om te onderzoeken welke problemen fysiotherapiepatiënten met diverse niveaus van gezondheidsvaardigheden tegenkwamen bij het invullen van de Patiënt Specifieke Klachtenlijst (PSK). De PSK werd als startpunt genomen voor de te ontwikkelen tool die later 'Talking Touch Screen Questionnaire' (TTSQ) werd genoemd. De inhoud van de PSK leent zich goed voor het helpen van patiënten bij het verstrekken van relevante informatie over hun gezondheidsprobleem aan de fysiotherapeut. Hij is erop gericht om de patiënt zijn belangrijkste beperkingen in activiteiten te laten selecteren en zijn eigen therapiedoelen te laten formuleren. Om in kaart te brengen welke problemen fysiotherapiepatiënten tegenkwamen tijdens het invullen van de PSK zijn cognitieve interviews afgenomen bij vijftientig Nederlandse en vijftientig Turkse fysiotherapie patiënten met diverse gezondheidsvaardigheid niveaus nadat zij de vragenlijst hadden ingevuld. De resultaten van deze studie, die beschreven is in **Hoofdstuk 2**, laten zien dat op één na alle respondenten problemen tegenkwamen tijdens het invullen van de vragenlijst. De meeste problemen waren gerelateerd aan het begrijpen van de vragen en de instructies. Dit leidde ertoe dat vierentwintig respondenten, van wie de meesten beperkt gezondheidsvaardig waren, niet-valide antwoorden gaven.

De resultaten van de studie die beschreven is in hoofdstuk 2 hebben geleid tot de tweede doelstelling van het onderzoeksproject. Dit was het ontwikkelen van een werkend prototype van de Nederlandse versie van de TTSQ. Dit werd beschreven in **Hoofdstuk 3**. Een co-design methode is toegepast, waarbij tien laaggeletterde mensen vanaf de start van het ontwikkelproces deel uitmaakten van het design team. Het betrekken van de gebruikers werd georganiseerd door middel van twee focusgroep sessies (analysefase), twee user walkthroughs (ontwikkelfase) en een gebruikerstest met een nieuwe groep laaggeletterde mensen (implementatie). Het ontwikkelproces resulteerde in een digitale applicatie op de originele iPad 1 met een 9.7-inch scherm. Een tablet computer bleek het meest geschikte apparaat te zijn om aan de behoeften van laaggeletterde mensen te voldoen, omdat het alle mogelijkheden van een computer heeft, maar er niet zo uit ziet en de bediening geen lees- en schrijfvaardigheden vereist. Vragen over pijn, locatie en pijn intensiteit werden aan de oorspronkelijke vragen van de PSK toegevoegd, omdat gebruikers primair geïnteresseerd waren in het rapporteren van hun klachten en niet hun beperkingen. Visuele (video's en foto's) en audio (spraak technologie) ondersteuning werd toegevoegd om participanten in staat te stellen om de vragen die op aparte schermen getoond werden te zien en te horen. Antwoordmogelijkheden konden geselecteerd worden door de touchscreen aan te raken en in alle geschreven en gesproken tekst in de TTSQ werd eenvoudige taal gebruikt. De resultaten van deze studie laten zien dat, los van de meer 'technische' ondersteuning, het belangrijk is om de sociale en psychologische aspecten van het invullen van vragenlijsten in ogenschouw te nemen bij het ontwikkelen voor laaggeletterde mensen. Op basis van de 'lessons learned' werden in hoofdstuk 3 richtlijnen gegeven voor het ontwikkelen van interactieve vragenlijsten voor laaggeletterde mensen.

De laatste doelstelling was om te testen of de nieuw ontwikkelde Nederlandse TTSQ accurate informatie over symptomen, beperkingen en therapiedoelen genereerde bij patiënten met diverse gezondheidsvaardigheidsniveaus in een fysiotherapie context en om de gebruiksvriendelijkheid van de Nederlandse en Turkse versie met elkaar te vergelijken. Om inzicht te krijgen in de mate waarin vierentwintig Nederlandse en elf Turkse fysiotherapie patiënten met variërende gezondheidsvaardigheidsniveaus in staat waren om de TTSQ te bedienen en hoe zij tot hun antwoorden kwamen werd de Three-

Step-Test-Interview methode van Hak en van der Veer gebruikt. Deze bevatte zowel think aloud als probing technieken. In **Hoofdstuk 4.1**, werd de juistheid van de informatie die gegenereerd werd door het gebruik van de Nederlandse versie van de TTSEQ in een Nederlandse fysiotherapie patiënt populatie geëvalueerd. De resultaten van deze studie laten zien dat het gebruik van eenvoudige taal en informatie en communicatie technologie (ICT) een positief effect hebben op de begrijpelijkheid van de vragenlijst. Het heeft echter ook enige negatieve effecten op de andere vier aspecten van het antwoord proces: interpretatie, informatie opdiepen uit het geheugen, beoordeling van de relevantie van opgediepte informatie en antwoordselectie. Door het gebruik van eenvoudige taal misten sommige vragen detail, waardoor ze multi-interpretabel werden. Multi-interpretatie was ook een probleem bij het gebruik van foto's als antwoord opties voor beperkingen in het dagelijks leven. Daarnaast zorgde het tonen van vragen en antwoord categorieën op aparte schermen zonder terugfunctie ervoor dat respondenten het overzicht over de gehele vragenlijst kwijt raakten. Dit maakte het moeilijker voor ze om te bepalen of ze al dan niet een antwoord moesten selecteren of door moesten gaan naar volgende schermen in de hoop dat die nog beter passende antwoorden zouden bevatten. Aan de andere kant maakte het geven van specifieke antwoordopties dat sommige patiënten niet meer actief in hun geheugen op zoek gingen naar informatie over situaties waarin zij beperkingen ervaarden vanwege hun gezondheidsprobleem. Deze problemen in het antwoord proces leidden tot niet-valide en incomplete resultaten bij twintig van de vierentwintig casussen. De participanten merkten de fouten en hiaten in hun antwoorden niet op, getuige het feit dat zij allemaal aangaven dat ze zichzelf in de uiteindelijke uitkomsten herkenden. De problemen die ontstonden waren niet verschillend per opleidingsniveau. In **Hoofdstuk 4.2** wordt de gebruiksvriendelijkheid van de Nederlandse versie van de TTSEQ geëvalueerd in een populatie van Nederlandse fysiotherapiepatiënten met diverse gezondheidsvaardigheid niveaus. De resultaten van deze studie laten zien dat alle vierentwintig Nederlandse participanten erg tevreden waren met de gebruiksvriendelijkheid en efficiëntie waarmee ze de vragenlijst konden bedienen. De gebruiksvriendelijkheid overtrof de verwachting van de participanten. De data met betrekking tot de effectiviteit lieten echter dertien verschillende problemen zien die zich voordeden tijdens de bediening van de vragenlijst. Volgens de ernstscore van Nielsen & Loranger, zouden negen van deze problemen

waarschijnlijk geen substantiële invloed hebben op het toekomstige gebruik van de tool, maar de vier andere problemen moesten wel geadresseerd worden voordat de Nederlandse versie van de TTSQ op de markt gebracht kon worden. Hoe lager geschoold en minder ervaren participanten waren in het gebruik van mobiele technologie, hoe meer problemen zij tegenkwamen. In **Hoofdstuk 4.3** wordt de evaluatie van het gebruiksvriendelijkheidsonderzoek van de Turkse versie van de TTSQ in een populatie van fysiotherapie patiënten met een Turkse achtergrond en verschillende niveaus van gezondheidsvaardigheden beschreven. De resultaten van deze studie bevestigen dat participanten met een lager opleidingsniveau en minder ervaring met het gebruik van mobiele technologie minder goed in staat zijn om de TTSQ effectief te bedienen. De meeste van de elf Turkse participanten, die over het algemeen lager geschoold en minder gezond waren dan de participanten in de gebruiksvriendelijkheidsstudie van de Nederlandse versie, waren niet uitgesproken tevreden of ontevreden over de gebruiksvriendelijkheid van de Turkse TTSQ. Twee Turkse participanten, die geen eerdere ervaring hadden met het gebruik van mobiele technologie, hadden het gevoel dat, ongeacht welke verbeteringen doorgevoerd zouden worden, zij nooit in staat zouden zijn om met de tool te leren werken. Zeventien verschillende soorten problemen werden gevonden, waarvan drie geadresseerd moesten worden tijdens de verdere ontwikkeling van de tool volgens de ernst-score van Nielsen and Loranger. Doordat het onderzoeksteam erin geslaagd was om zeer kwetsbare participanten in termen van opleidingsniveau, gezondheidsvaardigheidsniveau, ervaring met mobiele technologie, gezondheidsstatus en sociale status te werven, gaven de resultaten een goed beeld van hoe moeilijk het is voor deze groep om niet alleen met nieuwe technologie om te gaan, maar ook en misschien wel vooral, om te participeren in onderzoek.

In **Hoofdstuk 5** zijn de in dit proefschrift beschreven resultaten in een breder perspectief geplaatst door te reflecteren op het gebruik van vragenlijsten in de klinische praktijk in het algemeen en door zowel de onderzoeksmethoden als resultaten uit dit onderzoeksproject te vergelijken met andere studies van vergelijkbare tools. Uiteindelijk zijn aanbevelingen gegeven voor de praktijk en toekomstig onderzoek. Samenvattend kan gezegd worden dat het huidige prototype van de TTSQ nog niet alle problemen die beperkt gezondheidsvaardige autochtone en migranten patiënten tegenkomen bij het invullen

van vragenlijsten oplost. Hij moet verbeterd worden op zowel het gebied van gebruiksvriendelijkheid als validiteit. Veel werk moet nog gedaan worden om de TTSQ verder te ontwikkelen en te testen op zijn psychometrische eigenschappen. Grote uitdagingen in de toekomstige ontwikkeling en het testen van de TTSQ zijn de werving van kwetsbare leden van de moeilijk te bereiken autochtone en migranten doelgroepen en het vinden van onderzoeksmethoden die passen bij de behoeften en vaardigheden van deze participanten. Naar verwachting zal dit een erg uitdagend, arbeids- en tijdsintensief proces worden. Aan de andere kant kan het hebben van een gebruiksvriendelijke, valide en betrouwbare TTSQ wellicht een heleboel tijd en geld besparen in de toekomstige klinische en onderzoek praktijk. Als toekomstig onderzoek uitwijst dat het gebruik van de TTSQ kosten vermindert en de kwaliteit van zorg verhoogt, zou het investeren in de ontwikkeling van een TTSQ, die een groot aantal vragenlijsten in verschillende talen bevat, wellicht interessant kunnen worden voor zorgverzekeraars en andere investeerders.

De waarde en legitimiteit van standaardgebruik van vragenlijsten in hun huidige vorm in de klinische praktijk moet wellicht heroverwogen worden. Clinici zouden moeten eisen van onderzoekers en ontwikkelaars dat zij vertegenwoordigers van de volledige variatie van leden van hun doelgroep in hun onderzoek betrekken bij de ontwikkeling en evaluatie van gezondheid gerelateerde vragenlijsten. Als een vragenlijst niet getest is een onderzoekspopulatie die representatief is voor een 'real life patiënt populatie' met een variëteit aan gezondheidsvaardigheidsniveaus, zouden clinici erg terughoudend moeten zijn in het gebruik ervan in de klinische praktijk. De kans bestaat dat zo'n vragenlijst niet bijdraagt aan de kwaliteit van de informatie uitwisseling welke tot betere zorgverlener-patiënt communicatie leidt. Sterker nog, het zou de kwaliteit van de communicatie weleens kunnen verminderen en kunnen leiden tot ongewenste en dysfunctionele situaties.

Het is zeer belangrijk dat onderzoekers blijven streven naar de ontwikkeling van gebruiksvriendelijke, valide en betrouwbare vragenlijsten die gebruikt kunnen worden in onderzoekspopulaties die representatief zijn voor 'real life patiënt populaties', inclusief beperkt gezondheidsvaardige autochtone en migranten patiënten. Dit zal ten goede komen aan de generaliseerbaarheid en validiteit van door patiënten gerapporteerde uitkomsten in onderzoek.

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De overige consortiumpartners hebben eveneens een belangrijke bijdrage geleverd aan de totstandkoming en uitvoering van dit innovatie- en onderzoekstraject en wil ik hier daarom graag noemen. Anita Cremers (Lectoraat Co-Design en TNO), Kim Kranenburg (TNO), Helmi Duijvestein (Regionaal Genootschap Fysiotherapie - Midden Nederland), Jorien Bakx (NIGZ), Hester van Bommel, Marjolijn van Leeuwen, Geesje Tomassen (Pharos), Niels Groeneweg (Agis Zorgverzekeringen), Cor Hoffer en Mariette Hoogsteder (Mikado) en Jan Custers en Victorien de Graaf (KNGF), dank voor het vertrouwen en al jullie bijdragen.

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About the author

ABOUT THE AUTHOR

Curriculum Vitae

Marlies Welbie was born on July 31, 1978, in Waalwijk, Netherlands. After graduating from the Utrecht University of Applied Sciences as a Physical Therapist in 2003, she started working as a physical therapist in Amsterdam Osdorp, a deprived area of Amsterdam, because she was very interested in the effect low health literacy of native and migrant patients would have on the effectiveness of physical therapy. Because, at that time, little was known about this subject in the Netherlands, she started her education as a Clinical Health Scientist (Clinical Health Science, Physical Therapy Science in the Faculty of Medicine) at the University of Utrecht, while continuing work as a physical therapist. The central theme during this study was exploring the barriers and facilitators of effective physical therapy in low health literate patient populations. Her Master thesis resulted in a Dutch publication (first author) and she received her Master of Science degree in 2008. During the last year of her Master of Science education, she combined her work as a physical therapist with working as a lecturer at the Master's Program in Physical Therapy, specializing in Psychosomatic Physical Therapy, of the Utrecht University of Applied Sciences.

After she graduated as Master of Science, she started working as a research assistant at the University of Applied Sciences, Rotterdam, in the research group Work and Health and later on in the research group Primary Care. In 2009, she started working as a researcher in the research group Lifestyle and Health of the Utrecht University of Applied Sciences where she got the opportunity to raise funding and develop the research project that resulted in this current PhD thesis. Since then, she has combined research with lecturing activities, curriculum development and policy tasks which all are related to the subject of her research. In 2016, she changed to the research group Innovation in Health Care Processes in Pharmacology of the Utrecht University of Applied Sciences to share her knowledge about health literacy and qualitative research methodology.

Currently, she is working as a researcher in the research group Methodology of Practice-Based Research of the Utrecht University of Applied Sciences. She focusses on qualitative research methods, research integrity, functional and effective collaboration between

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researchers, professionals, policymakers and educators in practice-based research collectivities and professionalization of researchers and research facilities at the Utrecht University of Applied Sciences.

Apart from her work she is the proud mother of her two wonderful children, Cas (7y) and Luc (5y). She is living with her husband, Ingmar Reesing, and her two sons in Hilversum, Netherlands.

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Aarhus, Denmark, 2014

Physiotherapy in an intercultural setting through the eyes of the professional: a qualitative study

International Conference on Communication in Healthcare
Montreal, Canada, 2013

Physiotherapy in a intercultural setting through the eyes of the professional: a qualitative study

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Milaan, Italië, 2012

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NCVGZ congres
Amsterdam, 2012

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Bijeenkomst Regionaal Genootschap Fysiotherapie Randstad West
'Zelfmanagement altijd in het belang van de cliënt?'
Leiden, 2016

Health Literacy

International Week Integrated Care in Deprived Areas
Hogeschool Rotterdam
Rotterdam, 2016

Pijn en allochtone patiënten

Nascholing Vereniging Revalidatieartsen
Nijmegen, 2013

Gezondheidsvaardigheden

Promovendi dag ministerie van Buitenlandse Zaken en
Koninkrijksrelaties
Den Haag, 2012

De ontwikkeling van de Nederlandse Talking Touch Screen

Eindsymposium TransFysA-project
Lectoraat Leefstijl en Gezondheid, Hogeschool Utrecht
Utrecht, 2012

Laaggeletterdheid in Nederland. Wetenschap in de praktijk

Regionale Genootschap Fysiotherapie Midden Nederland
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Minisymposium Cultuur en Communicatie in de Multiculturele praktijk

Vakinhoudelijke avond Regionaal Genootschap
Fysiotherapie Midden-Nederland
Utrecht, 2008

De multiculturele fysiotherapiepraktijk; een fysiotherapeutisch perspectief

Vakinhoudelijke avond RGF Randstad West
Delft, 2008

Challenges of physiotherapeutic treatment of Migrant patients in Utrecht

Summerschool Jyväskylä University of Applied Sciences
Jyväskylä; Finland, 2007

AWARDS

Tweede prijs Univé Paludanus Prijs 2014

Project TransFysA Talking Touch Screen
Univé
Delft, 2015

Derde prijs RAAK-award 2013

Voor praktijk gericht onderzoek
Stichting Innovatie Alliantie, NWO
Den Haag, 2013

Genomineerd voor de Challenging Diversity Award 2011

voor mijn werk als beleidsmedewerker diversiteit HU
ECHO te Den Haag, 2011

