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**Mijn Máxima Plan: A Usability Study of an Informative App to Decrease Stress in Parents of
Children With Childhood Cancer**

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Abstract

Background: Today it becomes more and more important to provide patients with tailored information, to cope with the disease and prevent medical traumatic stress. This is also the case in the Princess Máxima Center for pediatric oncology where a new online patient portal (OPP) is being developed. In preparation for this Mijn Máxima Plan (MMP), an app, was developed to provide tailored information to families about the treatment of their child with a Wilms Tumor (WT). **Aim:** We investigated the usability and future use of MMP. **Method:** A mixed method design with interviews and questionnaires was used. Parents (n=13) were interviewed and filled in questionnaires before and after the use of MMP. Additionally, professionals were interviewed on their expectations of MMP in three focus groups (n = 32). **Results:** Results showed MMP has a high usability. Professionals were divided about the usability of MMP. Elements will be used in the OPP. The MMP matches with the high need of information which is expressed by parents. **Conclusion:** Information from MMP should best be provided at the start of the treatment, since that is the most stressful time of the treatment. There is a need for an overview about the complete treatment, including appointments with a concrete timeline and information about all treatment elements during their patient-journey. Elements of the MMP will be incorporated in the future OPP so all parents in the Netherlands with a child with cancer receive tailored information.

Keywords: Evaluation, pediatric, cancer, parents, coping, family centered care, e-health

Samenvatting

Achtergrond: Tegenwoordig wordt het steeds belangrijker om patiënten te voorzien van gepersonaliseerde informatie met ziekte en medisch traumatische stress om te gaan. Dit is ook het geval in het Prinses Máxima centrum voor kinderoncologie, waar een nieuw online portaal (OPP) wordt ontwikkeld. In voorbereiding hierop, is Mijn Máxima Plan (MMP), een app, ontwikkeld met persoonlijke informatie over de behandeling van het kind met een Wilms Tumor (WT). **Doel:** We hebben de usability en de toekomstmogelijkheden van MMP onderzocht. **Methode:** Een mixed method design met interviews en vragenlijsten is uitgevoerd. Ouders (n =13) werden geïnterviewd en hebben vragenlijsten ingevuld voor en na het gebruik van MMP. Daarnaast zijn er professionals geïnterviewd in drie groepen (n = 32) over de verwachtingen van MMP. **Resultaten:** Resultaten laten een hoge usability van MMP zien. Professionals laten

verdeelde resultaten zien over de usability. Elementen van MMP zullen gebruikt worden in het OPP. MMP sluit aan op de hoge behoefte aan informatie bij ouders. **Conclusie:** Informatie in MMP zou vanaf het begin aangeboden moeten worden, omdat dit de meest stressvolle tijd is voor ouders. Er is een behoefte aan een overzicht over de gehele behandeling, waarin afspraken in een concrete tijdlijn en informatie over alle elementen van de behandeling gedurende het behandeltraject zijn inbegrepen. Elementen van MMP worden opgenomen in het toekomstige OPP zodat alle ouders in Nederland met een kind met kanker gepersonaliseerde informatie ontvangen.

Sleutelwoorden: Evaluatie, pediatrisch, kanker, ouders, coping, family centered care, e-health

Mijn Máxima Plan: A Usability Study of an Informative App to Decrease Stress in Parents of Children with Childhood Cancer

Digital health information systems become obligatory in the Netherlands (de Jonge & Bruins, 2018) and it has become more and more common to provide patients with information through several types of e-health (Ybarra & Eaton, 2005). An important innovation in providing information is the development of an online patient portal (OPP) for all parents and patients of the Princess Máxima Center for pediatric oncology (the Máxima). With this OPP all parents of children with pediatric cancer will receive information about their treatment in a digital environment. Providing information adjusted to family needs is an addition to family centered care and adds to prevention of medical traumatic stress (Davidson et al., 2017; Woolf, Muscara, Anderson & McCarthy, 2016). In preparation of the OPP, Mijn Máxima Plan (MMP) is developed; a personalized digital application (app) to provide information about the treatment to parents of a child with a Wilms tumor (WT) - a solid organ abdominal tumor, which mostly occurs between the ages 1-4 years old (Kieran & Ehrlich, 2016). The goal of MMP is to decrease stress in these parents. After diagnoses, these children first receive chemo for a couple of weeks, then have remains of the tumor removed and after this removal the rest of the treatment will be decided.

The aim of this study is to investigate the usability of MMP and how it should be implemented in the OPP, so all parents of children with cancer in the Netherlands are provided with digital personalized information. Therefore the central question of this research is; whether the usability and perceived outcomes of MMP reaches its goals and how MMP should be implemented in the OPP.

Theoretical Framework

Parental stress in childhood cancer.

Pediatric cancer patients often experience more complications in their psychosocial functioning compared to their peers (Gurney et al., 2009; Lown, Philips, Schwartz, Rosenberg & Jones, 2015; Patenaude & Kupst, 2005). Next to the children, their parents may experience long term psychological complications as well (Grootenhuis & Last, 1997; Vrijmoet-Wiersma et al., 2008). These complications can be defined as Pediatric Medical Traumatic Stress (PMTS); a constellation of psychological and physiological responses of children and their families to pain, injury, serious illness, medical procedures and invasive or frightening treatment experiences

Kazak et al., 2006). PMTS is related to psychosocial outcomes. These psychosocial outcomes are for example anxiety, depression or posttraumatic stress. Most stress among parents is reported shortly after the diagnosis of their child (Vrijmoet-Wiersma et al., 2008; Woolf et al., 2016).

These psychological complications in parents can also have consequences on the development of the child. For example, PTSS in parents of children with cancer is associated with self-reported PTSS in children (Currier, Jobe-Shields & Phipps, 2009; Phipps, Dunavant, Lensing & Rai, 2006). Additionally, parental stress in these parents leads to more distress in the child, increased anxiety in the child and is associated with child psychopathology (Barakat et al., 1997; Okado, Long & Phipps, 2014; Phipps et al., 2006). Research shows that parental stress lowers the quality of life of children with cancer and is correlated with a lowered family functioning (Jobe-shields et al., 2009; Streisand, Kazak & Tereyak, 2003).

Information seeking as a coping strategy.

The mechanism parents use to adjust to PMTS is called coping (Last & Grootenhuis, 1998). Lazarus and Folkman (1984) defined coping as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of a person” (p. 141). According to Goldbeck (1998) there is a significant correlation between parent and child coping, where parents with a maladaptive coping-style showed low family cohesion and social withdrawal. Grootenhuis and Last (2003) studied stress management and defined several ways of coping. One way for parents to cope in a situation where their child is diagnosed with cancer is gaining information and trying to understand the disease of their child. This coping style, or cognitive control strategy, is defined as *interpretative control*, whereby gaining information and explanations about the treatment of the child gives a feeling of control which is stress reducing. In previous research it was shown that parents tend to use interpretative control frequently (Grootenhuis et al, 1996). Also parents often use *predictive control*, where parents need an overview and knowledge about the treatment.

E-health: digital provider of patient information.

Facilitated information through technology is called E-health (Sousa & Dunn-Lopez, 2017). Although most parents consider their child’s practitioner as primary source of information, research shows that most parents also use the internet as a source for information (Knapp et al., 2010). However, a lot of information on the internet is often of poor quality and not personalized (Grootenhuis & Last, 2003; Mackert, Kahlor, Tyler & Gustafson, 2009).

Additionally, research shows that people with high anxiety often search for health information online, but this sometimes results in more anxiety due to misinterpretation and confirmation of their already existing misbeliefs (te Poel et al., 2016). Research also shows that parents of children with cancer search a lot for medical knowledge and check the medical record of the child when this is available (Mueller, Cochrane, Bennet & Carroll, 2018). Mueller and colleagues (2018) found that caregivers of children with cancer highly desire an E-health tool that provides medical information. Also, as often changes occur in the treatment protocol of the child, parents need personalized knowledge to make important medical decisions. For these reasons, information should be in proportion and of good quality.

Usability of a digital innovation.

Digital E-health innovations should be carefully implemented to be effectively used by patients. Shackel (2009) defined *usability* of digital applications as “the capability to be used by humans easily and effectively” (p.340). Where *easily* means to a specified level of subjective assessment and *effectively* to a specified level of performance. Criteria used to measure usability are *attitude* (amount of satisfaction on the application), *effectiveness* (accomplishing the goals), *flexibility* (adaptation to personal situation), and *learnability* (learning time for users) (Shackel, 2009).

Mijn Máxima Plan: a personalized information app.

E-health enhances family centered care. Family centered care is an approach in care where the participation of families is supported (Crespo, Santos, Tavares, & Salvador, 2016). Since it is known that pediatric cancer is a stressor for the child as well as the parents, family centered care is considered essential in pediatric oncology (Kearney, Salley & Muriel, 2015). The Princess Máxima Center for pediatric oncology also provides family centered care, connecting with their ambition; ‘*To cure every child who has cancer, while providing an optimal quality of life*’ (Princess Máxima Center, 2017).

Mijn Máxima Plan is a tool to provide family centered care. When a child is diagnosed, the child and parents receive the protocol on one piece of paper. It provides the schedule of chemotherapy, operation and possible other elements in an overview with just a timeline. In 2016 a parent of a child with WT started visualizing the protocol of the treatment of her child. She expanded the protocol with information about every step during the treatment, and provided picto’s to help her family cope with the schedule in a daily life. She called it “the roadmap” to

the treatment of her child. The Máxima considered this tool as an option to provide families with additional information to guide them through the treatment in more dosed details. With a grant from FNO/Stichting Steun Máxima it was possible to outline all steps in detail, question parents about expectations and to develop the first prototype of an app to guide parents. The new name of this tool is 'Mijn Máxima Plan' (MMP). An elaboration on MMP can be found in appendix 1. The goal of MMP is to decrease stress in parents by providing information to promote interpretative control and predictive control.

Current study: aims and hypotheses.

MMP is practice based and developed according to the N=1 theory, which means that MMP is constructed after the needs of one family (van Yperen & Veerman, 2007). Now with the first prototype of the app available the aim of this study is to; study the usability of the app with three objectives:

- 1) Evaluate the usability of MMP by parents and professionals involved;
- 2) Analyze how MMP can be incorporated in a general OPP that is being developed in the Princess Máxima Center;
- 3) Gain insight on the perceived outcomes before and after the use of MMP.

Usability. To answer the first two questions, the *usability of MMP* has to be studied. Criteria used to measure usability are; *attitude* (amount of satisfaction on MMP), *effectiveness* (accomplishing the goals of MMP), *flexibility* (adaptation to personal situation) and *learnability* (learning time for users) (Shackel, 2009). Since information helps parents with coping, positive outcomes are expected on effectiveness and attitude. However, MMP is very textual and appointments do not automatically attune. Therefore, negative outcomes are expected on learnability and flexibility.

Also, the same criteria get evaluated among professionals that are going to use MMP. Therefore, they should have a positive attitude and MMP should be effective, flexible and learnable for them to handle as well. Expectations are that professionals have positive outcomes on attitude and effectiveness, and negative outcomes on learnability and flexibility. Also, measurements on the implementation of the OPP have to be done. Therefore the usability criteria should be aligned with the project leader of MMP and OPP to get insight in what both parents and professionals need to include MMP in the OPP.

Perceived parental outcomes. This pilot study will give preliminary insight in the possible success factors of MMP (van Yperen, de Wilde & Keuzenkamp, 2014). The perceived outcomes will be measured by outcome indicators of MMP. An outcome indicator is a topic that measures to what extent a goal is reached (van Yperen & Veerman, 2007). As mentioned above, the main goal of MMP is to decrease stress in parents by increasing their interpretative control. To achieve this, parents are provided with information about the medical treatment of their child. Additionally, MMP can be used as a diary with the aim to gain an informative overview on the treatment of the child. Following on the goals of MMP, the indicators to measure the perceived outcomes of MMP in this research are; *self-reported stress, need for information, communication with their child and family* and *perceived stress about the medical treatment*. Expected is that parents report a decrease in self-reported stress and in the need for information and an increase in communication with their child and family and perceived overview on the medical treatment after using MMP. Second, it is expected that professionals (e.g. pediatric oncologists) experience that parents have more knowledge about the treatment of the child and have more specific questions on the treatment of the child.

Methods

Design

Based on the practice-based character of this research, a mixed method design was chosen for this pilot needs assessment and evaluation study. The mixed methods ensured triangulation which increased the reliability and validity of this study (Baarda et al., 2013). Mixed methods can inform clinical practice since coping with pediatric cancer is a dynamic process that requires multiple methods to accurately assess and to understand families experiences (Hildenbrand et al., 2014). Quantitative (questionnaires) and qualitative (interviews and focus groups) data was collected from parents and professionals. Semi-structured interviews created the possibility to ask for clearance which reduced wrong implementation (Baarda, 2013). A visual display of the design of this research is shown in figure 1. With parents, two interviews and questionnaires were held to measure differences in the experience of families between T_0 (before the app trial) and T_1 (after the app trial). After parents gave informed consent, questionnaire T_0 and interview T_0 were held. After a trial of MMP, questionnaire T_1 and interview T_1 were held. With professionals focus groups took place.

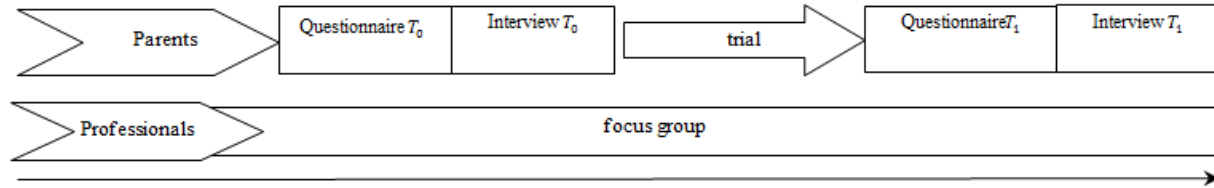


Figure 1. Design of the research

Since this is research in a medical setting, approval of the Dutch Medical Ethics Assessment Committee (METC) was needed. The METC has considered that this study does not contain proceedings mentioned in the definition of the WMO act (03-01-2019 / 18-881/C). Therefore, it is not needed to test this research on its content according to the WMO act.

Procedure and participants

Parents ($N = 13$, 8 women, 5 men, $M_{age} = 34$ years, age range: 28-42 years) from 8 children treated for WT participated. A flow-chart of the recruitment procedures is shown in figure 2.

Parents of seven children in treatment (Treatment Group: TG) were invited by the pediatric oncologist who was in charge of the treatment of the child, of which four families were included. An appointment for the first interview was made and the first questionnaire was sent to them by post, to fill in before the first interview. All interviews were held at the Máxima. During this meeting, the parents signed an informed consent. During the first interview, I gave the parents an instruction of MMP and parents received an iPad which contained MMP to use freely for four weeks. After these four weeks a new appointment for an interview was made. Parents filled in a questionnaire before the second interview.

Additionally, parents of five children out of treatment (Follow Up Group; FUG) were approached by the pediatric oncologist, of which four families were included. After consent, I called parents to participate. Parents of children out of treatment got a short demo of MMP and evaluated MMP for 3-4 hours at the Máxima, during their regular visit. Afterwards, they filled in a questionnaire and held an interview (T_1).

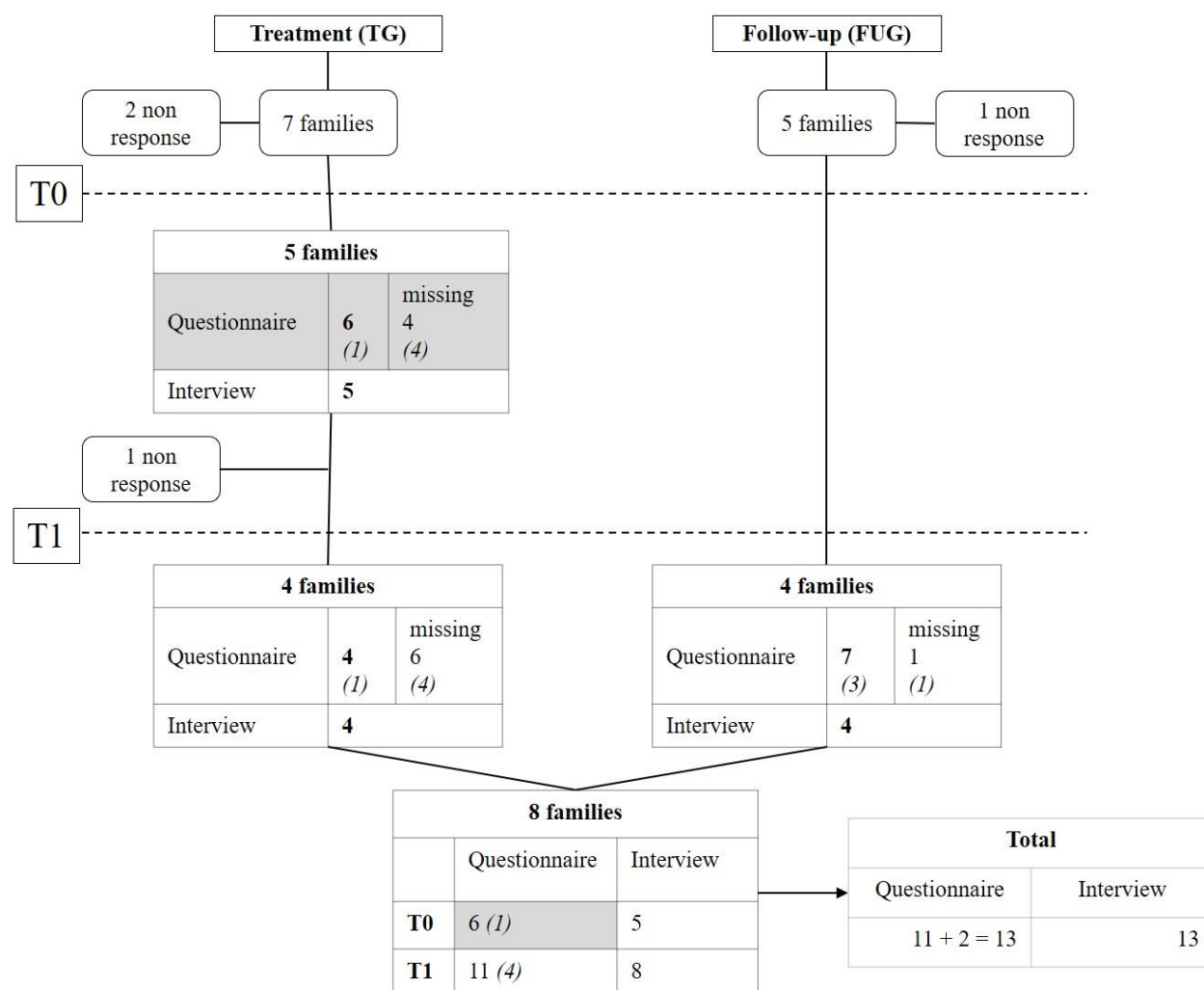


Figure 2. Participant flow chart of parents who took part in this study. Light grey areas are excluded data in the analyses. The bottom table shows the total included data for this study. Two questionnaires of T_0 were added in the analysis on perceived outcomes. Italic data show the quantity of fathers that filled in questionnaires.

Health professionals were interviewed in focus groups in their working environment. Professionals ($N = 32$) consisted of three groups; nursing specialists ($n = 5$), psychosocial team ($n = 12$) and pediatric psycho-oncology experts ($n = 15$). The interviews consisted of a demo of MMP presented by me, after which semi-structured questions were asked according to a topic list.

Measurement

The parent questionnaires were created using sub-scales of validated questionnaires on stress and coping which increased reliability and validity (Baarda, 2013). Individual and group

semi-structured interviews were held with topic lists that were created based on the literature on usability of E-health devices.

Questionnaires: Both parent questionnaires T_0 and T_1 had 29 identical items. To measure perceived outcomes the following questionnaires were administered: *Parental stress* (5 items); Emotion Thermometers (e.g. fear), Likert scale 0-10 (Mitchell et al., 2009). *Need for information* (7 items); 6 items out of interpretative control (e.g. I read a lot about the disease of my child) the Secondary Control Strategy Scale for Parents (CCSS-p) Likert scale 1-4 (Grootenhuis & Last, 1996), and 1 item provided by Smets (2018) about willingness to know as little or as much as possible about illness and treatment (0-10). *Communication with the child* (2 items); Communication Questionnaire (e.g. How often do you talk with your child about their disease?) Likert scale 1-4 (Stam, Grootenhuis & Last, 1996). *Overview on the medical treatment* (10 items); 10 items from the Pediatric Inventory for Parents (PIP) were used about disease related distress on the medical treatment (10) (e.g. talking to the doctor) Likert scales how often (1-5) and how hard (1-5) (Vrijmoet-Wiersma et al., 2010).

The second questionnaire T_1 additionally contained another 30 items based on a questionnaire study from Bol and colleagues (2013) in accordance with the project group of MMP (Likert scale 1-7) to gain information on the *usability of MMP*; *Attitude* (e.g. the app is interesting for me), *effectiveness* (e.g. the app provides me with new knowledge), *flexibility* (e.g. general information-specific information) and *learnability* (e.g. hard-easy).

Interviews parents: Both interviews T_0 and T_1 were semi-structured. The topics of interview T_0 were based on theories regarding *parental stress* (e.g. What was the most stressful time for you?), *the need for information* (e.g. How did you receive information about the treatment of your child?), *communication with the child and family* (e.g. How do you communicate with your child?) and *overview on the medical treatment* (e.g. How do you experience the overview on the medical treatment you have?). Second, a standardized introduction on MMP was told to the parents. Therefore, all parents got the same introduction about MMP. Parents were asked to look at the app and think aloud about what they saw.

Interview T_1 started with topics on changes in the indicators of perceived outcomes from the last interview (e.g. did you get information; did the MMP change your distress and did you encounter changes in your overview on the treatment?). Additionally, the topic list of interview T_1 contained topics regarding *attitude* (e.g. Would you recommend the app to other parents?),

effectiveness (e.g. Did MMP increase your knowledge?), *flexibility* (e.g. How did you use the app?) and *learnability* (e.g. Was MMP easy to understand?).

Focus group professionals: These focus groups were semi-structured. The first topics were about needs assessment: *the need for information* among parents (e.g. What lacks the provision for information at the hospital now?). Second, topics on expectations about the *usability of MMP* were constructed (e.g. What are your expectations on the app?). Third, a general demo of MMP was shown to the professionals. Next, specific topics were asked on usability of MMP: *attitude* (e.g. How do you feel about the app?), *effectiveness* (e.g. How do you think MMP helps parents?), *flexibility* (e.g. What do you think about the connection with the treatment in de app?) and *learnability* (e.g. Is the app easy to handle?).

Analyses

Gathered data from the interviews was transcribed, analyzed and coded in Nvivo 12. This data was coded in three phases; open, axial and selective (Baarda, 2013). After coding, these steps were run through again, to enhance a clear conclusion. Data from the questionnaires were analyzed in SPSS by analyzing descriptives. Hereby the operationalized concepts were used as guidelines. The qualitative data from the interviews with parents is exemplified (triangulation) with the quantitative data from the questionnaires. The subscales of the used questionnaires were analyzed by interpreting mean scale scores and mean items scores. Items with highest and lowest mean items scores were interpreted and further explained by the qualitative data. Because low sample size ($n = 4$) and missing data prevented analyzing change due to use of MMP by comparing the subscales of T_0 and T_1 , it was chosen to combine data and only analyze T_1 . Due to this the perceived outcomes provide us with information about the stress and need for information the families experience in general. Parents TG and FUG were merged with each other on usability and were compared on perceived outcomes.

Results

Usability and OPP

To answer the first two research questions, questions about the use of MMP were divided in four subscales; *attitude*, *effectiveness*, *flexibility* and *learnability*. Figure 3 shows the division of single items in the questionnaire and mean scores of subscales. The items and descriptives are displayed in appendix 2.

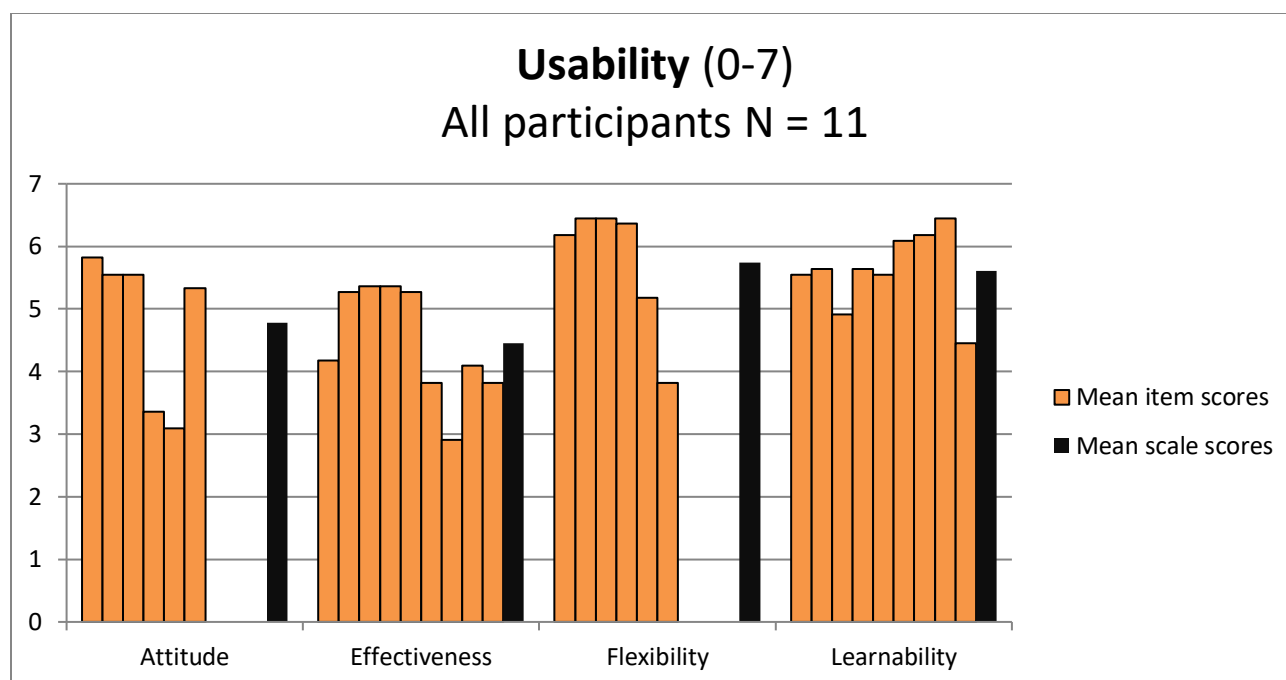


Figure 3. Mean scores on usability. Attitude (6 items), Effectiveness (9 items), Flexibility (6 items) and learnability (9 items). All questions were scored on a 7 point Likert scale. 11 participants filled in questionnaires on usability.

Attitude.

Attitude had a mean scale score of $M = 4.78$. Low scores were reported for text ($M = 3.36$) and pictures ($M = 3.09$): the MMP should have more text and more pictures. This is contradictory to the expectations, as it was expected that MMP consisted of too much text. Overall, the attitude on MMP was good. Both parents (TG and FUG) and professionals said MMP looked nice and consisted of clear language. All parents (TG and FUG) thought the general overview of the treatment and the examinations should be in the OPP. Parents TG used the information for a better understanding of the medical procedures, rereading information the doctor told them but in ease when they were at home, and explaining to other family members the treatment protocol of their child. Parents (TG and FUG) felt that they could trust the information from MMP since it was provided by the Máxima.

"I think it is good that we as parents have more control on what we are about to read. You can choose yourself what you want to read, when instead if I use the internet, I read the most horrific stories which do not even apply on my daughter her situation."

All parents would recommend this app to other parents because it was up to themselves how much information they wanted to read. However, some professionals were holding back on

the amount of information. Also, parents (TG and FUG) and professionals thought that receiving information on an app fits better in this generation than flyers. Additionally, it would be nice if MMP was available on their phone.

Professionals wondered whether the general overview in MMP could be used to explain the treatment instead of their usual protocol schedule of chemotherapy, operation and possible other elements. Although professionals liked the general overview, they thought it is important this overview can be adjusted to changes in the protocol.

Effectiveness.

The mean of the effectiveness scale is $M = 4.45$. The highest mean item scores are “The app gives me more knowledge” and “The app helps me better understanding the disease” ($M = 5.36$). However, the item; “MMP helps me with my emotions” ($M = 2.91$) scored low. In the interviews some parents said MMP would have been stress reducing if all their appointments would have been lined up automatically. Parents (TG and FUG) said they would have preferred MMP at the start of the treatment of their child, since that was the time they looked most on the internet for more information. Professionals were divided in sharing this opinion. According to them too much information may increase stress and anxiety. Also, since all parents (TG and FUG) who participated were already post-surgery, they already knew what to expect. Although for some parents MMP would prevent searching for information on the internet, other parents said they read new medical terms that they could search for on the internet.

“I am somebody who searched everything on the internet. If this was the best hospital for my child. Or if we should go to America, because I heard that America has a good treatment, or not. So all this information would help, but it would not have stopped me from searching the internet.”

Flexibility.

Flexibility scored high ($M = 5.74$). Most items in this subscale were about whether parents thought MMP was pleasant and fitted their personal situation. Parents (TG and FUG) all said that it was good to read information on WT, since it is hard to find information for that specific treatment online. They all felt like it was personalized information in which they could choose themselves how much they wanted to read. Professionals did not think MMP could be very personalized because protocols often change due to complications. They wondered whether MMP can be adjusted to those changes. Parents (TG and FUG) and professionals were positive

about reading the child's name in the information and suggested to also add the names of the practitioners. MMP also has an option in which the preferences of the child in certain medical procedures can be adjusted. Parents (TG) found it confusing that the preferences can be personalized but that these are not communicated to the hospital. And professionals do not think these preferences can be executed once these are connected to the patient portal. Additionally, the preferences were not completely relatable because some of the questions were not applicable for the child.

“Oh, my daughter always gives blood through her Porth-a-Cat, so the preference is not venipuncture or finger prick, but that is not an option here. Does the nurse see this?”

The information on the overview of the treatment would have been nice at the start of the treatment, because it creates an overview on what to expect. The overview was mainly used to explain the treatment to other family members.

“It is nice that I am able to just give the iPad to someone instead of telling the whole story again.”

The periodical view was not used. Some parents did not even remember this page of MMP. Both parents and professionals said it was confusing because the Máxima uses week numbers in treatment, where MMP uses week numbers of the year.

The appointment overview was received as unclear. Parents said they were confused because they all had to put the dates of the appointments in themselves, where they did not know which appointment was which. Although some parents mentioned it was good to look back to what already has been, this was already satisfied by the general overview. None of the parents (TG) filled in previous and upcoming appointments. The most information parents (TG and FUG) read was from the page with examinations and medical procedures.

“When my daughter started with a new chemo therapy, I read about that chemo, possible complications and how I could help her with that. It was very clear information. That was good. But I only read about it two or three times. After that I knew how she was going to react on the treatment and I knew what the information said. So maybe the information does not have to be that elaborated in every appointment, because you know after a while.”

Learnability.

From the questionnaires, learnability ($M = 5.61$) scored high on how easy ($M = 6.09$), clear ($M = 6.18$), and intelligible ($M = 6.45$) MMP is. Parents and professionals said it was not

hard to understand the structure of MMP. However, parents (TG) were confused by filling in the code about the treatment protocol and filling in appointments. The code further personalizes the information adjusted to the treatment protocol the child is having. Also, parents and professionals did not understand the weeks in the periodical overview. However the general overview was easy to read and it was clear of what phases the treatment contained. The information about the specific examinations and medical treatments was described as clear, good to read and not too much.

“I read it with my mom (the grandparent of the child) and it helped her understanding with what we are going through. I also showed the nurse of the shared care hospital. She did not know the exact protocol of a Wilms tumor, so she said it was very clear information.”

But MMP was not information they could read quickly in between tasks throughout the day. Parents TG said that they had to sit down for it and read it with concentration. The pictograms of the examinations and medical treatments were good. Several parents mentioned they liked the “Chemo Kasper” in the corner of the chemo pictogram, which is a character used to explain chemo therapy to children. Parents were divided on the link to the website of Princess Máxima Center. Some of them found it nice that they got directed to the corresponding website for more information. Others found it confusing that they got directed out of MMP.

Remaining results on usability.

Overall parents (TG) all were very satisfied with the amount of information they received from their treatment team. Some of the parents said they received even more than they expected as standard. After the trial parents (TG) said they did not use MMP a lot but it was nice to sometimes read about new treatments or about what the oncologist had said in an appointment. Parents (TG and FUG) wanted information online instead of flyers. When asked what they would like to see back in the OPP, parents said that they would like to have the appointments automatically connected, the general overview to see where they are, to explain the treatment to others and the specific information on medical procedures. Parents would have liked to have some interaction in MMP. Suggestions were; videos of procedures they could show their child, vlogs of doctors and experiences of other parents. At last, all parents (TG and FUG) thought MMP would be used more if the app was available on their phone.

A recommendation from the professionals was to add a button in which parents can choose themselves how much information they want to read. Parents and professionals would

like the app to be adjusted to children as well, but it is hard to adjust this to the several developmental stages of children according to the professionals. Therefore, ideas were to add pictures to the information. This can be shown to children and to parents who do not speak Dutch. A recommendation was made to make the text able to “copy-paste” so it could be translated online. The OPP has to be available on smartphone and has to be more adjustable to the protocol the child follows. Other recommendations were phone numbers of practitioners and synchronization with the personal agenda of parents.

Perceived Outcomes

Self-reported stress.

As shown in figure 4, parents in treatment score high on stress and tension ($M = 5.83$, $SD = 2.50$, range = 1-8) and anxiety ($M = 5.67$, $SD = 3.83$, range = 1-10). A trend is visible in lower scores on these items at follow-up, when children are out of treatment, which shows that parents then experience lower stress and tension and anxiety.

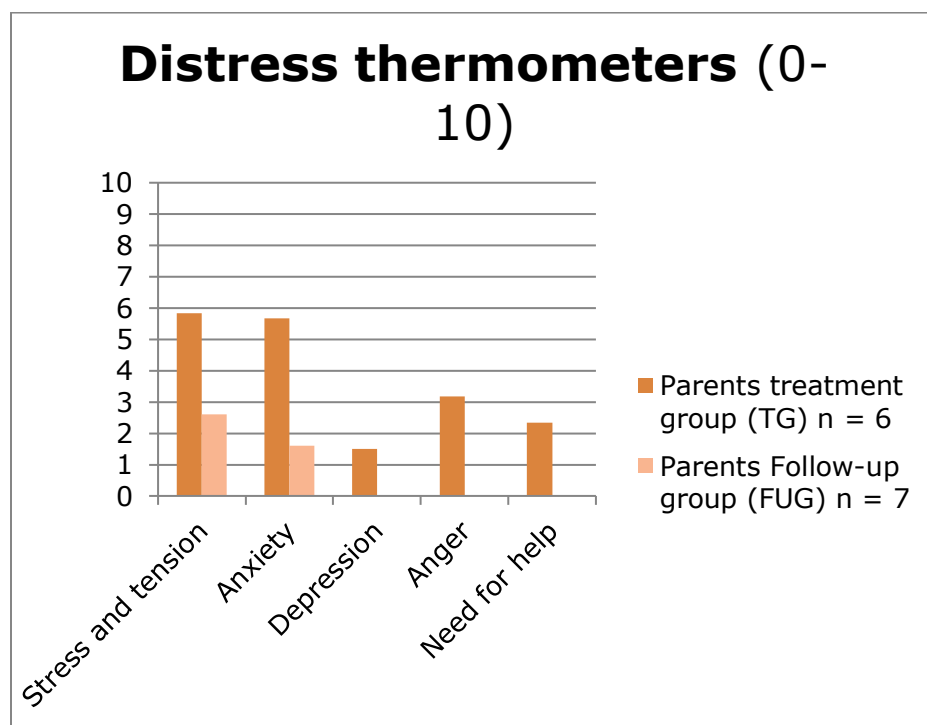


Figure 4. Mean item scores on distress thermometers (Mitchell et al., 2009). Likert 0-10 scale. The mean scores of Parents FUG were 0 at scales; Depression, Anger and Need for help.

When asked about stress in the interviews, parents (TG and FUG) said the first week after diagnosis was most stressful and that the stress decreased once they got clarity on the treatment.

Parents (TG) said MMP did not help in reducing stress at the trial period because they already had a lot of information and the child had gone through several weeks of treatment already. If they had received this information earlier in the treatment of their child they imagined that the app would be stress reducing. Parents reported that they also would experience the app being stress reducing if their appointments would be in the app automatically instead of manually. One of the participants said:

“Sometimes I have to check my mail and scroll through all the mails I get from the planning office and figure out which appointment I have to be at what time and then sometimes it changes. I guess it would be handy if it is all organized in one app instead of all those mails.”

Need for information.

The indicator *need for information* shows that parents (TG and FUG) score high ($M = 3.44$) on wanting to know everything about the disease and treatment. All item mean-scores are in the range 2.83-3.43 on a 1-4 point Likert scale (appendix 3). With these scores above average ($M = 2$), it implies the need for information is high. The item from Smets (2018) also scores high ($M = 9.22$, $SD = .97$), which shows there is a high willingness to learn more about the disease of their child.

This corresponds to the interviews where parents (TG and FUG) said they were advised by the medical staff of the Máxima not to search online, however all of them did anyway. Since a WT is a rare form of cancer, they found it hard to find information online on that specific treatment. Parents reported that they received clear information on the treatment of their child from their practitioners, but lacked in practical information on the treatment e.g. how a MRI goes. After the trial parents reported that MMP helped in reading about the treatment, since they cannot remember all the information of their conversation with the oncologist. One of the participants said:

“It is not that I do not listen to what the doctor says, but it is a lot of information to remember. It was nice to read again what the doctor said at night when I was home.”

Communication with the child.

All parents said they wanted to communicate with their child, but since most children are very young, this was hard. This shows in the results of the communication questionnaire ($M = 3.07$). Some parents said they read books with their child about the treatment in a playful way. None of the parents felt they lacked knowledge on preparing their child on the treatment, or to

inform siblings and other family members on the treatment. However, more information on specific aspects of the treatment would have helped, especially in the first week.

“Normally, people do not need a CT-scan. If I had known that I was allowed to be with my son during the CT-scan and that he had to lay with his arms above his head, it would have been nice to prepare him. But now it was hard because I even did not know what to expect.”

During the trial TG parents used MMP to communicate with friends or other family members. Especially the general overview on the treatment was perceived positively.

“My parents understood where we were in the treatment and what was to come when I showed them the treatment overview. It was hard to explain in which phase of the treatment we were, but with the app they understood better.”

Overview on the medical treatment.

These items were only answered by the TG parents ($n = 6$). Based on the questionnaire it is hardest for parents to be with their child during the medical treatment ($M = 3.33$) and to bring the child to the hospital ($M = 3.00$). The relationship between ‘how often’ and ‘how hard’ a specific situation is for parents is made visible in appendix 3.

In the interviews parents already experienced an overview on the treatment during T_0 , because diagnosis was already a few weeks earlier. Families knew where and when they had to be at the hospital. Also, most families have a social network to help with babysitting siblings and social workers from the Máxima helped them with organizing parents’ jobs in combination with the treatment of their child. At T_1 it was asked how MMP helped in creating an overview at home. Outcomes were that parents did not use the periodical overview of MMP a lot and that they did not use the overview of the appointments (because these were not up to date). Parents did not feel more overview at T_1 than T_0 . However, it was mentioned several times that the app would have helped in planning, if the appointments were linked automatically instead of manually in the app and if the app would have been available on their phone.

“I would have used the app more if the appointments were linked to the planning office automatically. I do not take the time to put all the appointments in my own agenda and in the app. If it would connect automatically it would be nice to look back sometimes to what she already had and on what dates she had appointments.”

Discussion

The goals of this research were to gain an understanding of the usability of MMP and the possible impact on the perceived outcomes of MMP to indicate in what way MMP could be incorporated in OPP for all patients of the Princess Máxima Center. This is a first pilot study which evaluates the usability of a new tool for parents to get overview on their child's treatment protocol

Usability and OPP

Regarding the usability of MMP in an OPP the results corresponded to the hypothesis that both parents and professionals reported positively on effectiveness and attitude. MMP will be more stress reducing if parents will receive MMP from the start of the treatment and if appointments are automatically connected. On flexibility and learnability results showed that only inserting appointments by parents themselves was perceived as negative on the learnability. Another remarkable finding is in the code that can be activated to personalize MMP more. Since this code was not used and not understood, it seems that the code decreases the learnability and flexibility in MMP. This makes MMP less easy according to Shackel's theory (2009). On the other hand, on flexibility parents (TG) reported that the information fitted their situation. This makes MMP work more effectively according to Shackel's standards (2009). Professionals agreed that MMP is personalized, but added that the protocol often gets adjusted caused by complications. MMP should be able to keep track of those changes, otherwise parents receive wrong information (Mueller, 2018). Another note on flexibility is the language. It was expected that MMP was too textual. However, results show that Dutch parents were satisfied with the vocabulary the text was written in, which makes MMP more easy according to Shackel's theory (2009). This is remarkable because this was an expected barrier of MMP and also mentioned as a barrier by professionals. It is important to make MMP available to be read in several languages because of the high sociocultural diversity in backgrounds in the Netherlands. A possible suggestion for the future is to make "copied-pasted" possible in a translate program, which makes use for international parents possible.

Perceived Outcomes

The third goal of this study was to gain a preliminary effect on perceived outcomes for MMP. We could only assess stress and information needs on one time point but with two groups. Stress and need for information decreased already since diagnosis, although for TG parents it

was higher than for FUG. The qualitative results show that parents think MMP might be stress reducing if they received MMP at the start of the treatment, because the first week was most stressful. These results are in line with the theory (Vrijmoet-Wiersma, 2008).

It was also expected that there would be a decrease in the *need for information*. Results are in line with this hypothesis since parents reported in the interviews that MMP probably would decrease their search for information on internet since MMP is a trusted source, which is in line with Mueller's theory (2018). Remarkable is that professionals tend to be careful with the amount of information they want to provide to the parent, which connects to the theory of te Poel and colleagues (2016) that information can cause more stress and anxiety due to misinterpretation. However parents want to decide themselves how much information they read, which connects with the coping theory of Grootenhuis and Last (1997) that says gaining information is a way of coping (interpretative control) during stressful situations. There appears to be a gap between professionals and parents in their vision on the need for information. Additionally, even though all parents (TG and FUG) mentioned they searched online for information, all parents (TG) were content with the amount of information they already received from the Máxima.

Next, expected was an increase in the *overview on the medical treatment and less disease specific stress*. Parents thought MMP might be stress reducing if their appointments were added automatically. That would create an overview on the medical treatment, which fits the theory of predictive control (Grootenhuis & Last, 2003).

On *communication with the child and family* it was expected that parents had experienced an increase in communicating with their child. However, because of the young age of the children with a WT, parents felt that they had enough knowledge to talk with their child. Results show that it would have been nice to include pictures or videos so they could use the information to inform their child better on the medical treatment. Unexpected, TG parents reported that explaining the treatment to their social network improved by showing MMP. Also, communicating with the practitioner may be improved by MMP, since results show that parents were helped by rereading information they got earlier from the practitioners since conversations contain a lot of information to remember.

Strengths and Limitations

Strengths in this research were that I was able to include a group of parents in a vulnerable position over a period of four weeks to participate in a pilot study. Most parents invited, decided to participate which increases the representativeness of this research. Next to parents, several stakeholders (professionals) with different expertise participated on the usability of MMP since they will be working with an OPP as well. The use of mixed methods (triangulation) increases the internal validity of practice based research (van Yperen, et al., 2014) by doing qualitative and quantitative research. This minimized wrong interpreting. However, this research also had some weaknesses. One of this weaknesses was that the limited sample size prevented robust statistical analyses. However, since subscales of validated Dutch questionnaires were used based on empirical theories, the internal validation is enlarged. Another limitation were the missing questionnaires which resulted in a limited execution of our third aim. Also, a limitation is that we were not able to start the MMP trial in the first week after diagnosis, since parents and literature mentions this is the most stressful and uncertain time of the treatment (Vrijmoet-Wiersma et al., 2008). However, inviting parents to participate after their most stressful weeks is more ethical. There also were complications with using the code of MMP to personalize the information.

Societal Implications

Implications for professional practice that can be extracted from this research are that MMP is tested positively and parents want to use it in practice. However, the information should already be provided at the start. Despite parents are content with the information they receive, it appears helpful to be able to read information over again. It is worth to develop MMP in an OPP because parents tend to look for more information online and on their mobile phone rather than flyers. Tools as MMP can be used by professionals for providing information to parents. Also, professionals can expect better informed parents with MMP. When MMP in the OPP complements flyers parents already get, professionals should use MMP as a tool for explaining the treatment to parents.

This study provides insight in the evaluation of MMP when it is used in a clinical setting, which contribute to the development of improving e-health. Wiener et al.(2015) plead for the development of broadly implementable interventions which can be tailored to the needs of families. With the development of medical care and increased survival rates, more focus in

research goes out to the psychological effects of cancer (Wiener et al., 2015). However, tools for the psychological well-being for families with an ill child are still rare. Next to scientific relevance, this study is also of social relevance since more and more children and parents have to live with the consequences of pediatric cancer as a result of increased survival rate (Magnani et al., 2006; Wiener et al., 2015).

In the future, MMP should be incorporated in the OPP with the adjustments that are suggested in this study. For future research there should be a pilot study of OPP with a large sample. Since there is not a lot of research done on e-Health and the effects of digital health information systems, research should be carried out since e-Health becomes the standard in more and more medical environments. Since this group is in a vulnerable, stressful situation, these studies have to be done carefully. Also, there should be future research on the gap between the need for information parents have and the amount of information professionals think parents should have.

Research shows that family support and the well-being of parents are of great influence on the well-being of the child (Lau et al., 2014; Meeske et al., 2013). A decrease in stress for parents in a stressful situation has positive outcomes for the well-being of the child (Gurney et al., 2009; Lown et al., 2015). Therefore, the relevance of this study is that positive outcomes for the well-being of parents of children with cancer, have better outcomes for the contribution of the child in society in adulthood (Barakat, Schwartz, Reilly, Deatruck & Balis, 2014). Providing parents with information and an overview works stress reducing. The outcomes of this research are important because parents of 600 children every year in the Netherlands may be helped in coping with their stressful situation with an optimal OPP. There is a need for an overview on the complete treatment, including appointments with a concrete timeline and information about all treatment elements during their patient-journey. This will contribute to an optimal quality of life.

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Appendix 1:



Mijn Máxima Plan

Wat is mijn Máxima Plan?

Mijn Máxima Plan is een app voor de Ipad. Deze applicatie is gemaakt om gezinnen inzicht te geven in het behandelplan van het kind.

De applicatie is gemaakt om te onderzoeken hoe we ouders van informatie kunnen voorzien die beter is af gestemd op de behoefte en de persoonlijke situatie van het gezin.

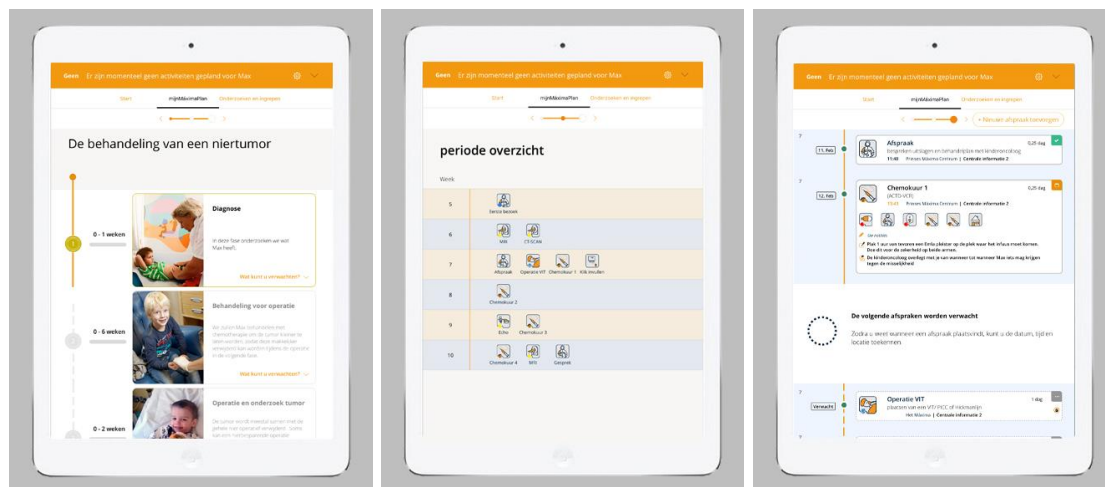
De app zal voorlopig als aanvulling op de bestaande informatie gebruikt worden.

Het voordeel ten opzichte van bestaande informatie is dat in de app informatie interactief is. Zo kan de app beter rekening houden met de specifieke situatie van een kind en in de tijdlijn alleen informatie geven die op dat moment relevant is.

Wat biedt mijn Máxima plan?

Een plek waar alle informatie bij elkaar komt en informatie terug te vinden is wanneer u het nodig heeft.

De mogelijkheid om de tijdlijn van de behandeling te volgen.

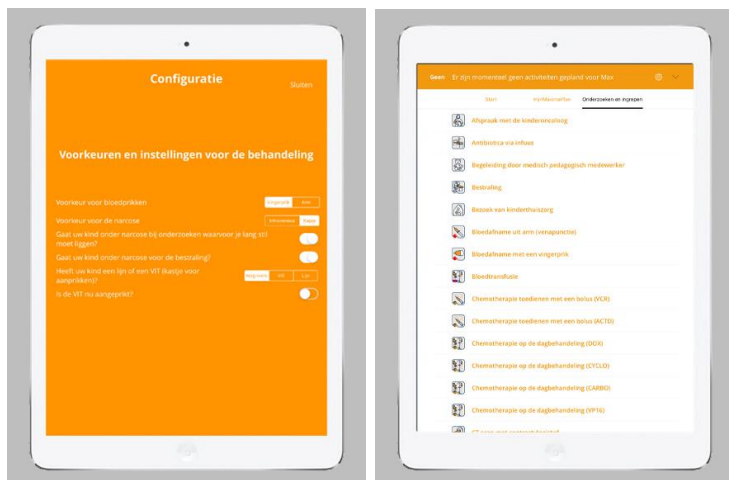


Algemeen overzicht

Periodieke overzicht

Afsprakenoverzicht

MIJN MÁXIMA PLAN



Persoonlijke voorkeuren

Onderzoeken en ingrepen

Een fase van de behandeling vrijgeven

De behandeling van een nier tumor bestaat uit verschillende fases, bij diagnose is nog niet bekend hoe de hele behandeling er voor een kind uit gaat zien.

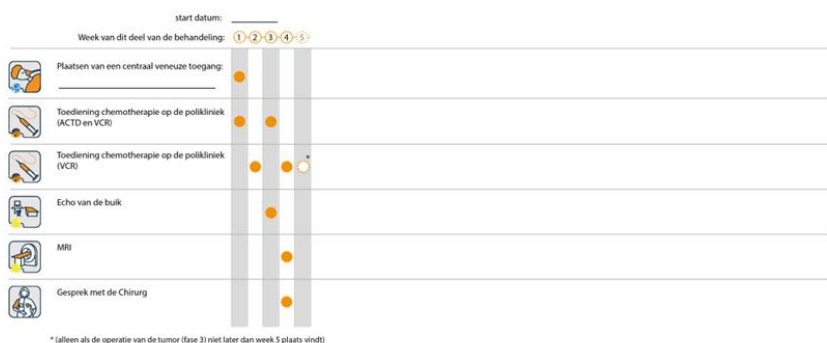
Aan de hand van uitslagen van verschillende onderzoeken bepalen we hoe het behandelplan in de volgende fase(s) er uit ziet.

Wanneer de arts de behandeling voor een volgende fase met u besproken heeft kunt u een briefje krijgen met een code om in mijn Máxima plan de volgende fase vrij te geven.

De volgende instructie geeft aan hoe u die code in kunt voeren in de app.

Fase 2: Pre- Operatieve behandeling voor Wilms tumor stadium I-III

Uw kind wordt in de komende weken behandeld met de peroperatieve behandeling voor Wilms tumor stadium I-III. Hier onder ziet u waar deze behandeling in grote lijnen uit bestaat.



Wilt u deze behandeling inladen in de app; mijn Maxima Plan?

Ga dan naar instellingen en klik op het menu activeer een pad. Voer de code WTPREOPW4 in en de datum waarop de eerste chemotherapie plaats zal vinden.

Appendix 2: Scaling items usability (n=11)

Attitude

<i>Item</i>	Min.	Max.	Mean	SD
<i>De app is mooi</i>	4	7	5.82	.87
<i>De app is voor mij interessant</i>	3	7	5.55	1.70
<i>De app wordt door mij gewaardeerd</i>	3	7	5.55	1.91
<i>Meer tekst – Minder tekst</i>	1	5	3.36	1.21
<i>Meer plaatjes – Minder plaatjes</i>	2	4	3.09	.83
<i>De app is goed ontwikkeld</i>	1	7	5.33	1.67

Effectiveness

<i>Item</i>	Min.	Max.	Mean	SD
<i>De app geeft mij vertrouwen in de behandeling van mijn kind</i>	1	7	4.18	1.66
<i>De app helpt mij beter voorbereid te zijn op de behandeling van mijn kind</i>	1	7	5.27	2.05
<i>De app breidt mijn kennis uit</i>	3	7	5.36	1.29
<i>De app helpt mij om de ziekte van mijn kind beter te leren kennen</i>	2	7	5.36	1.43
<i>De app geeft mij mogelijkheden om inzicht te krijgen in de ziekte van mijn kind</i>	1	7	5.27	1.68
<i>De app helpt mij om te gaan met stress</i>	1	6	3.82	1.47
<i>De app helpt mij met mijn emoties</i>	1	6	2.91	1.58
<i>De app geeft mij zelfvertrouwen</i>	2	7	4.09	1.45
<i>De app geeft mij rust</i>	2	5	3.82	1.17

Flexibility

<i>Item</i>	Min.	Max.	Mean	SD
<i>Lelijk – Mooi</i>	4	7	6.18	.87
<i>Niet aangenaam – Aangenaam</i>	6	7	6.45	.52
<i>Niet professioneel – Professioneel</i>	6	7	6.45	.52
<i>Aantrekkelijk – Niet aantrekkelijk</i>	6	7	6.36	.51
<i>Algemene informatie – Informatie sluit aan op onze situatie</i>	4	7	5.18	1.25
<i>Te veel informatie – Te weinig informatie</i>	1	6	3.82	1.33

Learnability

<i>Item</i>	Min.	Max.	Mean	SD
<i>De app is voor mij begrijpelijk</i>	1	7	5.55	1.64
<i>Het taalgebruik op de app is voor mij makkelijke te begrijpen</i>	1	7	5.64	1.12
<i>Toevoeging van een afbeelding zal de tekst verduidelijken</i>	2	7	4.91	1.51
<i>Toevoeging van een videofragment zal de tekst verduidelijken</i>	4	7	5.64	1.12
<i>De leesbaarheid van de app is goed</i>	3	7	5.55	1.70
<i>Moeilijk – Makkelijk</i>	5	7	6.09	.94
<i>Niet duidelijk – Duidelijk</i>	4	7	6.18	.98
<i>Niet begrijpelijk - Begrijpelijk</i>	5	7	6.45	.82
<i>Te veel details – Te beknopt</i>	3	7	4.45	1.13

Appendix 3: Scaling items Need for information and Disease related distress

Disease related distress: Medical treatment (PIP) Likert 1-5

	Sample	How often		How hard	
<i>Item</i>	(n)	(M)	(SD)	(M)	(SD)
<i>Mijn kind naar het ziekenhuis brengen</i>	8	2.88	1.13	2.75	1.28
<i>Opletten of mijn kind moeite met eten heeft</i>	8	2.88	1.81	2.17	1.17
<i>Bij mijn kind zijn tijdens medische ingrepen</i>	8	3.88	1.55	3.00	1.20
<i>Besluiten nemen over de medische zorg of medicatie</i>	8	3.13	1.64	2.67	1.51
<i>Mijn kind helpen bij de lichamelijke verzorging zoals wassen</i>	8	4.88	.35	1.29	.76
<i>Omgaan met veranderingen in de dagelijkse medische routines</i>	8	2.00	1.60	1.50	.84
<i>Helpen met medische handelingen</i>	8	3.13	1.64	2.33	1.21
<i>Naar mijn kind kijken tijdens bezoeken aan de dokter of medische ingrepen</i>	8	3.62	1.50	2.38	1.76

Need for information

Smets (2018) Likert 1-10	<i>Item</i>	Sample (n)	(M)	(SD)
	<i>Ik wil alles weten over de ziekte van mijn kind</i>	9	9.22	.972
CCSS-P (1998) Likert 1-4				
	<i>Ik vind het belangrijk alles over de ziekte van mijn kind te weten</i>	13	3.69	.86
	<i>Ik praat met anderen die hetzelfde hebben meegemaakt</i>	13	2.92	1.12
	<i>Ik wil precies weten hoe het gaat met de gezondheid van mijn kind</i>	13	3.69	.95
	<i>Ik kan de situatie beter aan als ik precies weet wat er aan de hand is met mijn kind</i>	13	3.77	.83
	<i>Ik lees veel over de ziekte van mijn kind</i>	13	3.00	.91
	<i>Ik wil alles over de ziekte van mijn kind goed begrijpen</i>	13	3.69	.75