Technology for Transition

Needs and preferences of young patients

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Abstract—**This paper presents a study of the technology needs of young patients with Irritable Bowel Disease, who are in the process of transitioning from pediatrics to adult-centered healthcare. The study is part of a Participatory Design process and is based on the assumption that information and communications technologies can potentially support young patients in achieving increasing independence from parental support and in engaging with their own healthcare. We argue in favor of designing for context-awareness and appropriation in technologies for young patients in transition.**

Keywords- Participatory Design; IBD; ICT needs; context-aware; appropriation

I. INTRODUCTION

Today, more than 90 % of children born with chronic or disabling conditions will survive well beyond their 20th birthday due to the advancements in medicine and treatment [1]. As they mature, young patients' personal and medical needs change and in their late teens they transition to the adult clinic or ward in order to receive age-appropriate care [2]. Transition in healthcare is being defined as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented healthcare systems" [3] and is triggered by the age of the patient. Before the actual transition, "adolescents are prepared to assume responsibility for their care" [4] because there are important changes in the way care is provided [5]. While pediatric providers rely on input from the young patient's family and have a more holistic approach to care, adult-centered healthcare providers communicate exclusively with the adult patient and present a more fragmented healthcare system. Applebaum et al. [6] argue that a seamless transition process is critical to the future health of the young patients; flaws in this process may lead to worse health outcomes. Adolescents with medical needs seldom make a smooth transition to adult healthcare [1]. Hence, transition has gained much needed attention during the past decade and has been described as "one of the greatest challenges facing peadiatricians" [7].

In a period already characterized by major physical, psychosocial, and social changes, young patients face additional challenges having to deal with changes in the way healthcare is provided [5] and "loose respected and loved carers and are forced to trust new and unknown ones" [8].

Because of their vulnerable position, young patients face a greater risk of dropping out of the healthcare system, which may have adverse health consequences. As a major life stressor, transition may also have direct negative health outcomes especially in case of diagnoses where psychological stress can increase the likelihood of relapse, such as Inflammatory Bowel Disease (hereafter, IBD) [2].

A growing body of evidence suggests that information and communication technology (hereafter, ICT) and technology-mediated methods hold the potential to improve outcomes for people with chronic conditions [9]. ICTs are especially promising in case of young patients who tend to be technology savvy and enjoy using new technologies. In terms of altering behavior, it is especially important to target this population, as it is during adolescence that adult behaviors are established and hence represent an opportunity to promote health oriented behavior and influence the healthcare needs of tomorrow's adults.

As we will discuss later in this paper, downloading a mobile application is not equivalent to using it. While not problematic in the context of regular apps, this issue presents a considerable challenge in health-oriented solutions, where positive health outcomes are dependent on consistent use.

This paper presents research on mHealth use and preferences for transition-oriented ICTs among a group of young people with IBD. The aim of the paper is to explore young patients' perspectives on *what*, *when*, and *how* technology can play a supporting role in transition.

The remainder of this paper is organized as follows. In the next section, we briefly present the existing trends in improving the transition process. Section III describes our methodology, methods, and population sample used to obtain the results, which we present in Section IV. In Section V, the main part of this paper, we discuss our results and the implications they might have for the design of technology for transition by using the concepts of context-awareness and appropriation. Finally, in Section V, we present some concluding remarks and opportunities for future work.

II. BACKGROUND

Existing initiatives surrounding transition can be divided into three categories: i) *guidelines and recommendations*, ii) *paper- and form-based tools*, and iii) *mHealth and eHealth initiatives*. Guidelines form a large body of literature,

proposing ways to help patients gain the necessary knowledge and skills to become competent in adult services and make decisions about their care. Important elements of successful transitions are a) cooperation between pediatrics and adult medicine, b) enabling the young patient to be part of the decision-making and management of their healthcare as early as possible, c) balancing parental support with the need for independence, d) continuity of care, and e) health education [6].

The recommendations stress that the barriers to achieving good transitions are not adolescents but the limitations of the healthcare itself. Acknowledging transition as a process rather than a singular event or transfer, Blum [3] was one of the first to suggest that the process should be initiated when the patient is 13 years old. Aiding the patient in planning and initiating the work towards independency in adult medicine, a range of paper-based tools has been developed. A transition checklist has been designed and implemented by The Royal Children's Hospital Melbourne and has been adapted by several Norwegian hospitals. Similar tools, such as health passes and 3 questions (Hospital for Sick Children, SickKids, Toronto) encourage young patients to learn more about their conditions and prepare for doctor's appointments.

There is a unified consensus that transition is an important challenge for both pediatrics and adult medicine. However, little has been done to implement the abovementioned guidelines and recommendations for transition. The growing demands are met with scarce resources in capacity, budgets, and healthcare professionals. This has contributed to the recent growth in the number of mHealth initiatives or healthcare supported by mobile technologies. Teens and young adults are an especially relevant group of potential users as they are tech savvy and enjoy using mobile technologies, making mHealth suitable and promising in terms of improving healthcare. TransitionMate which offers reminders, self-assessment of health and emotional state, and suggestions for health promoting activities [10], and Healthy Transitions which consists of video training sessions and quizzes [11] are two mobile applications targeting medical transition. As part of their ongoing research, [12] have presented various platform-based considerations for designing a transition app. There is a considerable number of ICTs focusing on IBD. Among these we find myIBD, developed specifically for *young patients* by SickKids, which focuses on logging and managing symptoms.

III. METHODOLOGY

Young patients, especially during their teenage years, tend to separate their identity as a patient from their identity as a teenager [13]. In order to meet them in a context where they felt comfortable to talk from a patient perspective, we conducted our research while they received treatment at the Children and Youth Clinic of Akershus University Hospital (AHUS) and the Medical Gastroenterology Clinic of the Central Hospital in Vestfold (SiV), respectively. The focus of the study was to understand transition from a patient's perspective and investigate *whether*, *where*, and *when* technology could play a supporting role in this process.

A. Participatory Design

There exists a lack of understanding of the teenage agenda and the challenges they face in transition – both as patients and adolescents [1], [14]. This study has therefore taken a Participatory Design (hereafter, PD) approach as it "takes into consideration the needs, interests and abilities of the youngsters, but also includes a more profound interest in their hopes, fears dreams, and opportunities to express themselves as someone of importance" [15]. With a focus on understanding *knowledge by doing*, the study was based upon PD's principles of *having a say, mutual learning* between the participants and researchers, and *situated action* [16].

B. Methods

For the purpose of this study, we used a closed sort [17], card-based method that we have described extensively in [18]. The method, called Transition Cards (TCs), is a qualitative card sorting method that enables participants to express their expectations and experiences surrounding transition. The TCs were used during individual interviews, in which we asked the participants to sort 70 cards representing *people*, *things*, *skills*, and *feelings* into categories representing *pediatric ward* ('BUK'), *adult ward* ('Voksen'), and *both* ('Begge'), which represented things relevant across these wards (see Figure 1). The cards referred both to the participants' identity as a patient, as well as to their life outside the hospital, thus providing a holistic approach to understanding transition [18].

Figure 1. A participant's use of the Transition Cards representing *things*.

C. Recruitment and participants

Recruitment of the participants was undertaken by the head of research at AHUS and by the staff at the Medical Gastroenterology Clinic at SiV. The participants were recruited while receiving treatment at the clinic and the medical staff decided whether the patients were well enough to participate. The patients received an information sheet, as well as a consent form, which they read before meeting the

researcher. Once they agreed to participate, the researcher would meet them and both the researcher and the participant signed the forms. In the case of patients under the age of 16, a legal guardian also had to sign the consent form.

The research was registered and approved by the ethical board at both hospitals, and the Norwegian Social Science Data Services (NSD).

D. Sample

Participatory Design calls for involvement of future users based on the motivation that they are the sole experts on their needs and practices that the design should support. However, designing for a process that the future users have not undergone yet or know much about, required the involvement of patients who had transitioned. Therefore, the sample consisted of pre- and post transition patients.

An acceptable sample size in qualitative research studies involving participants with impairments or other vulnerabilities is between 5 and 10 [19]. In this study, fifteen young patients participated in this study – 8 pre-transition (ages 13-17) and 7 post-transition (ages 18-25) out of whom six were male and 9 female.

IV. RESULTS

The interviews provided important information for mapping the young patients' expectations and experiences with transition and the role of ICTs in supporting them in any of the challenges that they presented and discussed using the Transition Cards. It was also important to understand which technologies they were using the most and what they used them for. We therefore started all interviews with asking whether the participants had access to mobile phones, computers/laptops, and tablets. All of the interviewed patients owned smart phones and only one out of fifteen did not own a computer. Majority of the participants had access to tablets, but reported on using mostly laptops and mobile phones. The participants reported that they used their phones for social media, such as Instagram, Facebook, Snapchat, Vine, and mobile applications offering instant messaging. The participants used their computers for schoolwork, gaming, and social media.

When mapping their use of health applications, several participants conveyed that they were advised by their doctors to download the 'IBD app' developed by a Norwegian company. Once downloaded, few of them tried to use the app but stopped due to the problem of too many notifications and reminders to log their symptoms or to enter a symptom-free period. Other health apps used by the participants were Endomondo and other training apps, and menstrual calendars. One of the participants reported on using an app to log migraine episodes and headaches.

In addition to ideas for more youth-friendly adult wards, the participants also proposed several areas where they thought that new technology could play a supporting role in their transition and life as a patient. These areas and needs can be categorized as *information, medical dictionary, reminders,* and *health rights and financial support.*

A. Paperless Information

Only seven of the patients received information about transition at least a year prior to their transfer. Two of the interviewed teens received the paper-based checklists during what was their last visit at the Child and Youth clinic. Majority of the interviewed patients suggested sites or apps presenting information about the new ward and an explanation of the differences in routines and practices of their old clinic and the new ward. Getting information about what they could expect at the adult wards, such as different specializations, having to engage with different doctors as opposed to their own pediatrician at the pediatric wards, could reduce some of the uncertainty. The pre-transition patients, who were informed about transition, were told that the adult health services were managed by the nurses and not by the doctors. They mentioned that they did not fully comprehend what it meant.

The patients suggested that the information about the adult wards should not only inform the patients about what would be different with regards to the above-mentioned changes, but also with regards to the changes in routines specific to their diagnosis. Conditions related to the digestive system often require endoscopic examinations, which in pediatric wards are performed under anesthesia. Anesthesia is not offered to adult patients, but they can receive temporary sedatives. The participants felt that they should be informed about this prior to the transfer in order to avoid stress and fear. The expressed need for diagnosis-specific information on transition is not the same as need for information about the diagnosis, and in particular the outlooks and life expectancy. Two of the participants expressed that it was too scary to think about the severity of their diagnosis, and that they did not read about the diagnosis online to avoid confrontation with information on this matter.

In addition to information about the different practices, the patients wished to be able to see the wards – ideally in person and accompanied by the personnel from the pediatric ward, but pictures or videos were considered helpful as well. Because the treatment and examinations were offered at different wards and clinics, the patients also thought that a map they could have on their mobile phones would help them in finding their way around the hospital.

We asked the patients about how they wanted to be informed about new health-oriented ICTs. Posters in the pediatric and adult medicine wards were suggested as a good way of spreading the initiatives. Another important factor was confirmation of the legitimacy and origin of the technology by the healthcare professionals.

B. Medical Dictionary-app

Two of the younger participants suggested medical dictionaries containing explanations for difficult words, acronyms, and treatments. When asked whether they would like to learn difficult terms through games, quizzes or textual explanations over time, the patients expressed that they needed information when difficult terms came up during their consultations and stay at the hospital, indicating that the information should be easy to find – even without knowing

the correct spelling and be short enough so they could deal with the information also during the consultations with the medical staff.

One of the post-transition patients shared her experiences with not understanding what a stoma bag was, which affected her treatment decisions. She discussed a possibility of offering images or videos of treatments to show patients what they really looked like in order to reduce fear and uncertainty. As one of the younger participants explained, *When they call it 'blah blah', you don't get any of it. It sounds like gibberish or turns out to be something else than you thought. (...) So that it said what it was. It would be easier to understand what they put in your body. (...) I think it's weird that you get stuff put in your body that you don't know what it is* (girl 13).

C. Reminders for mobile devices

A large part of becoming an adult and being responsible for one's own healthcare is taking charge of appointments and medications. Today, Norwegian hospitals routinely send out text messages reminding the patients about their appointments at the hospital in addition to a letter. Remembering appointments with general practitioners are still the patients' responsibility. Several of the participants suggested reminders as desired functions on their mobile devices. The reminders would help them to remember their appointments and to take their medications. Reminders during the holidays and while travelling were highlighted as especially useful as different routines and time zones would often cause the participants to forget their medications especially if they had to be taken at specific times of the day.

D. Information on Health Rights and Financial Support

The Norwegian healthcare system offers free healthcare to persons under the age of 16. Upon turning 16, patients start to pay a deductible when receiving healthcare services, have the right to confidentiality, and can make decisions surrounding their treatment. When patients turn 18, they lose their right to free appointments with a child and youth psychologist. On the other hand, the Norwegian Welfare system offers benefits and financial subsidy for adults with chronic conditions.

Two the interviewed patients voiced a need for ICTs offering information on health rights targeting pre-transition youth. In addition, several post-transition patients reported on suddenly having to learn about health rights during the course of their transition.

E. Platforms

Both websites and apps were suggested as good platforms for information. One of the participants explained that: *You can take an app or cell anywhere, but a website is better for information. So both are important* (boy 17). The choice of platforms for the suggested tools was closely coupled with the purpose and context of use. While websites were explained as great for learning and reading up on things, apps were preferred where information was supposed to be offered immediately - without the need of internet connection. The participants suggesting the medical dictionary as a technology for transition argued that it would have to necessarily be an app so that they wouldn't have to rely on an Internet connection, which was often scarce at the hospital. Only one of the participants suggested paper-based brochures containing information, and none of the participants perceived the checklists offered at the hospital as helpful. One of the participants explained: *"it sucks more when it's on paper. I don't know why but I feel that it more serious and stuff like that when it's on paper, that you have to read through everything that will happen. It's certainly easier on a website"* (boy, 17).

F. Social networking

To our surprise, none of the participating patients suggested a patient-social network or other means of connecting with other patients in a similar life situation. However, they proposed that especially information sites should have comment fields so that others could discuss the topics or share their experiences. Several participants reported on reading blogs by other patients, but shared their concern about the reliability of the information, and relevance for their own situation – especially in cases of rare or multiple diagnoses, the participants were not able to relate or gain new knowledge from experience-based information found online.

V. DISCUSSION

Transition is situated between the different contexts and stages in life of adolescents. The process involves changes in how healthcare services are provided, different legal rights, and growing economic responsibilities. It also involves responsibilities related to growing up and becoming an adult and, above all – being a young person – not a patient. [20] argues that despite the dominant role of their condition, they do not see themselves as patients. When designing and implementing measures to aid them in aspects connected to their patient identity, it is important to understand their daily life and how technology can fit there.

Powell et al. [21] imagine medical practitioners prescribing apps alongside medications. The patients interviewed in this study reported on their doctors recommending them to download and use the "IBD-app" developed by a Norwegian company. The "IBD-app" can remind the patients to take their medications and recommend booking appointments on the basis of their logged symptoms. The participants downloaded the app, but reported that they didn't use it because the app sent out too many notifications and urged them to log their symptoms when they were in a symptom-free period. Although they expressed the need for a reminder app, the IBD-app required them to log their symptoms in order to access the rest of the functionalities. The youth participating in this study did not adopt and use the IBD-app over time and hence did not experience the full functionality and benefits of the app. This stands in contrast to the research suggesting that combination of tracking tools, with mobile technologies makes it easier for users to keep track of the different aspects of their health. Based on the participants' explanations, the prescribed app

did not offer them the experience they were looking for and became intrusive in periods when they did not have the need for its functionality. In other words, the app did not react to the patients' dynamic life-situation and lost its instrumental value when interfering with their non-patient identity. Dey [22] argues that today's technologies lack the ability to use and adapt to the situational information, or *context*, in the same way humans do. Context is defined as "any information that can be used to characterize the situation of an entity" [22, pp.5]. Further, [22] argues that having the ability to access and adapt to context will lead to better usability and usefulness of ICTs. In relation to technologies for transition and managing one's health, the understanding of context may help in determining *what, when,* and *how* we want to support.

A. When to support

The timing, or chronological age context, for introducing different ICTs and functions is crucial for adoption. The majority of patients suggested the timing for introduction of the information regarding transition to be close to the transfer. This is in contrast with what is suggested in the literature, which proposes the introduction of information between the ages of 12 and 14. As one of the teens explained: *When you're 14, it's still four years until you'll move, so it's not so important to know so much about it then* (girl, 17).

This aversion toward planning and preferences toward instantaneous and relevant ITs can be explained from a biological perspective. The ongoing re-structuring of the brain and development of cognitive abilities is not completed before reaching the mid-twenties, causes notable differences between adults and adolescents in their ability to control impulses, make rational decisions, and affects long-term planning [23]. This bio-developmental perspective combined with the findings in this study affects the overarching context of technologies for transition and indicate a need for technologies that are either context-aware, as defined by [22], and provide relevant information based on for example the user's age, location, and condition; or technologies developed specially for a relevant period during transition, which excludes the possibility and motivation for persistent use. Developing multiple technologies specifically for relevant periods of transition poses challenges with regards to sustainability and maintenance of these technologies and adds to the already high number of available apps and sites, making the task to find legitimate and relevant technologies harder for the users.

B. How to support

Another approach to this issue is to focus on appropriation. Within the field of PD, appropriation is being described as "the way that users 'take possession' of a technology innovation over time" [24]. As PD is concerned with giving users a say, appropriation becomes a way for users to "control and shape technologies to their own ends" [25]. Appropriation becomes especially relevant in the context of ICTs directed toward promoting health and supporting patients in managing their condition and care.

This is due to the claim that appropriation involves *mutual adaptation* [14], where the users shape technologies and technology shapes the users' practices. We propose that the process of *adaptation* holds the potential to produce context-aware technologies through users directly shaping and controlling the technology to fit with their current context, whether it is chronological age, physical and emotional condition, or physical or social environment. The majority of the health-oriented ICTs focus on the condition of the patient. However, when focusing on the context, our design interest should shift towards inclusion of health and wellbeing alongside the chronic condition. When meeting a healthy person, humans don't tend to inquire about their symptoms – doing so would be unnatural. Similarly, context-aware technologies should be designed to stop collecting data when patients are symptom-free or are within physical or social contexts where they are detached from their identity and responsibilities as a patient.

One of the patients used an app to log migraine episodes and headaches. She reported that she found the app very useful to make sense of what triggered her migraines. Why did then the "IBD-app", which was recommended by the doctors - a source preferred by the participants, not receive the same response? We believe that the motivation for adaptation and the perceived usefulness affected the non-adaptation of the IBD-app. Combined with the intrusive reminders to log their symptoms, the IBD-app was not perceived as useful even though it offered reminders, which the patients interviewed in this study showed an interest for.

C. What to support

The spaces for initiatives and designs proposed by our participants – the medical dictionary, information on transition and their legal rights, signaled that there is a need for information on the *practicalities* of transition on mobile and web platforms. When trying to support the informational needs of patients, we need to balance our literature-based knowledge on transition, which focuses on transition as a continuous process [6], with the patients' perspective on transition as a series of fragmented events with specific and practical implications – such as turning 16 and having to pay a deductible. An example of practical information could be to *(One could) write what the routines were in relation to meals and visiting hours* (girl 21).

Based on our results, we need to support the information needs of the patients aware of the context in which *they* want to acquire this information. Turning toward the patients' perspective allows us to discover that there is also a need to inform young patients about the benefits of transitioning; *Treatment is more efficient here* (boy, 21). *Actually I think that the whole arrangement was more complicated when I was downstairs at the children's ward because there were so many people around me that I had to deal with – here things are a bit simpler* (girl 22).

The requirement for contextual and developmental awareness needs to be balanced with the requirement for privacy. The interviewed patients, as well as the findings from our earlier studies [13], suggest that young patients value their privacy and any technology aimed at health or

extending the reach of healthcare institutions needs to be based on the values of confidentiality, privacy, and patient-centeredness.

VI. CONCLUDING REMARKS

There are no diagnoses with the exact same course for all patients – all diseases affect unique bodies at different points in life, and are triggered by different events in patients' lives. There is therefore a need for technologies that are aware of and will adapt to these lives and contexts. By designing for appropriation, the technologies may achieve context-awareness and hopefully shape the practices of the users by themselves allowing to be shaped.

In our future research, we aim to work towards understanding how we can implement context-awareness and facilitate appropriation in already existing technologies, as well as in the transition app, which we are currently developing in our ongoing research. We hope that this study will inspire designers, as well as healthcare professionals to work toward understanding the needs and context of young patients and design solutions that support them on their way toward independency.

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