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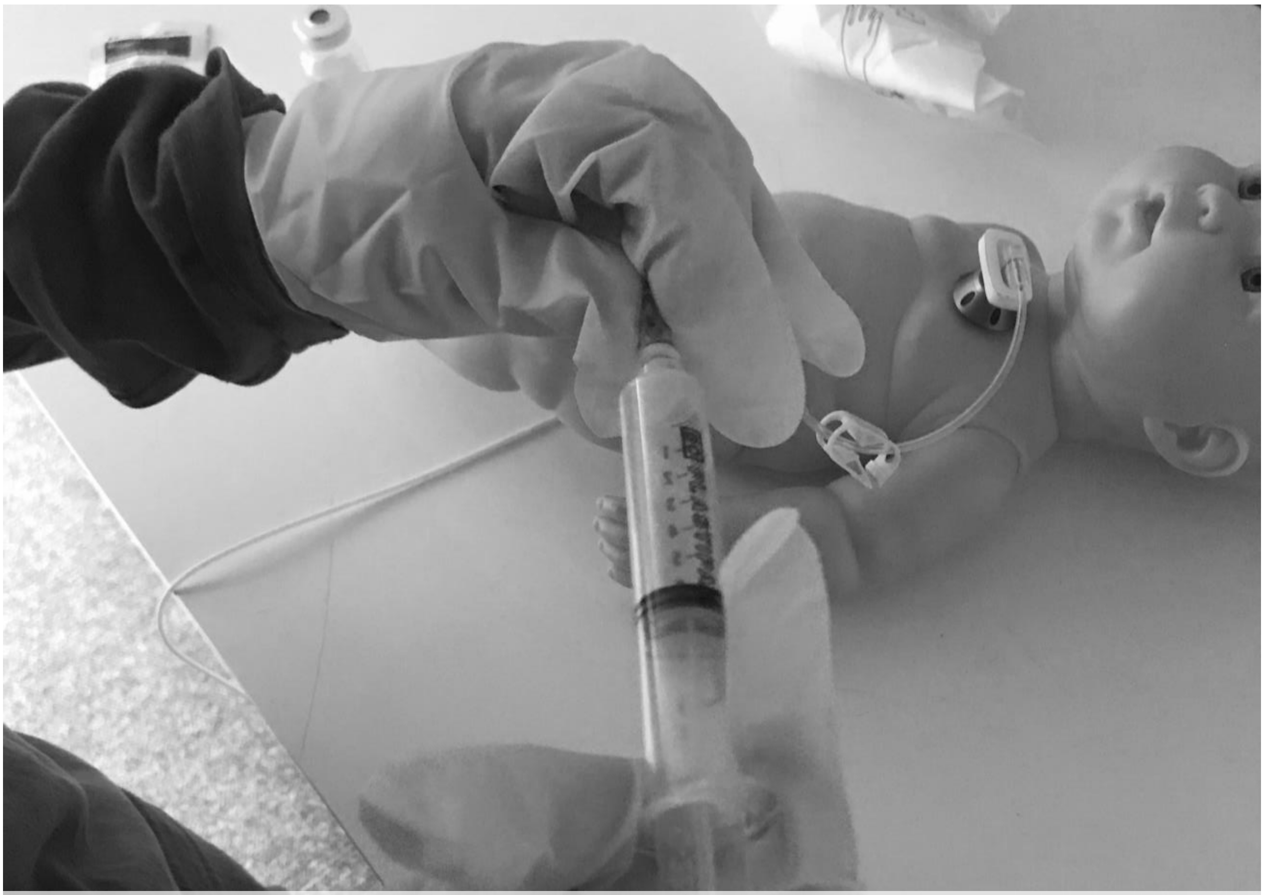

Minority report on mobile health technologies

An ethnographic exploration of mHealth innovation's *troubled attuning* to children and young people that live with chronic illness

PhD Thesis

Claudia Maria Bagge-Petersen

Primary supervisor: Henriette Langstrup

This thesis has been submitted to the Graduate School of Health and Medical Sciences,
University of Copenhagen, December 15, 2021

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Section for Health Services Research
Department of Public Health
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Academic supervisors:

Henriette Langstrup, Associate Professor, MSc Psychology, PhD
Anne Frølich, Clinical Professor, MD, PhD
Morten Skovdal, Associate Professor, MSc International Child Health, PhD
Jakob Eg Larsen, Associate Professor, MSc Computer Science

Assessment committee:

Professor Ezio Di Nucci (*Chair*), University of Copenhagen, Denmark
Associate Professor Stine W. Adrian, Aalborg University, Denmark
Professor Jeannette Pols, University of Amsterdam, The Netherlands

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Front cover: photo by author during fieldwork

Preface

This thesis is the product of my interest in how the emerging field of digital health technologies is attentive to children and young people that live with a chronic illness as are a particular kind of user of these kinds of technologies. The thesis is neither technophobic nor technophile. It neither attempts to villainise mHealth innovation, nor exaggerate this fields' possibilities in supporting illness management. It neither seeks to victimise children and young people, nor exalt their capabilities of managing illness. It is nurtured by a curiosity in relations between technologies, design, materialities, practices, humans, knowledge, methods, structures, incentives, norms, and values, both in terms of how such relations are established and when they are supposed to be established but are not. The thesis thus inscribes itself into a tradition of science and technology studies and specifically into research concerned with health and illness. The study is however also strongly inspired by the feminist scholarly movement in research to unfold bias and inequalities inherent in knowledge and technology production. It aims to put children and young people that live with chronic illness on the agenda of science and technology studies and into the innovation field of digital health.

Acknowledgements

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I felt the need for this thesis to exist in the world while working in The Telemedical Knowledge Centre of the Capital Region of Denmark. Thank you, Judith Lørup Rindum, for supporting my idea and for making this financially possible. Thank you also to Cachet for the financial support and for facilitating an inclusive environment for PhD students of all kinds, interested in digital health technologies.

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Thank you, Makker, for always having a crazily high belief in me while at the same time keeping my attention on the important matters – only you can do both. Thank you, Trine, for caring and asking considerate questions. Thank you, far, for keeping interested in my work, for being proud of me, and for spoiling me during writing in your summerhouse. Thank you, Elke, Arnd, Dubi, Miriam, Jannick, and Oldefar, for being the kindest, most helpful, engaged, and supportive family-in-law.

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English summary

This study explores how mobile health smartphone applications (mHealth apps) are designed and attuned to children and young people that live with chronic illness. mHealth apps make it possible for patients to monitor their illness continuously in everyday life, and is predicted to be valuable for increasing patients' illness self-management, direct healthcare services towards the individual patient's needs, and to improve health outcomes. Yet the evidence for mHealth apps' abilities to integrate into the lives of paediatric patients and improve illness management and health outcomes is mixed. This study aims to investigate how mHealth design processes consider the particular circumstances of children and young people and their everyday lives with chronic illness.

To investigate the attuning of mHealth apps to children and young people that live with chronic illness, a multi-method ethnographic fieldwork was conducted across the site of children and young people diagnosed with either haemophilia of juvenile idiopathic arthritis and the site of two mHealth design projects targeting these two patient groups. The generated empirical material covered written fieldnotes and photographs of children's and young people's everyday life with chronic illness and transcripts of focus group discussions among children and young people, parents, and a hospital youth panel. Furthermore, it included transcripts of interviews, fieldnotes, photographs, and a variety of collected materials with the mHealth projects. The empirical material was analysed through thematic network analysis to determine themes of the individual sites of children and young people living with chronic illness and the mHealth design projects and also enable analysis across them.

The key finding of the study was that there are various troubles in attuning mHealth apps to the particular circumstances that characterise children and young people and their ways of living with chronic illness. The results showed considerable discrepancies between how the mHealth projects purposed their designs and the ways in which children and young people practice and perceive their lives with chronic illness. It furthermore showed that the mHealth projects' design methods gradually limited the projects' capabilities to account for children and young people as a particular kind of user until excluding them as target users entirely in favour of an adult patient group. The mHealth projects' challenges in recognising and adjusting to the lived realities of children and young

people were associated with larger structural and visionary ideas about patients' abilities to manage and live with chronic illness.

The results suggest that mHealth innovation can marginalise children and young people that live with a chronic condition because the design processes are firmly anchored with patient ideals, design methods, and purposing that is exceedingly connected with adult patient populations. mHealth innovation can thus come to imply embedded 'adult defaults' that considerably troubles the attuning of the technological designs to children and young people. On this basis, mHealth projects should be attentive to the driving forces of the innovation context that they are part of which might bias the design towards some groups and against others. Furthermore, the field of mHealth innovation should seek out opportunities for enabling explorations of children and young people's lived realities and specific societal positions to inform the digital health design processes.

Dansk resumé

Dette studie udforsker, hvordan smartphonebaserede applikationer til sygdomshåndtering (mHealth-apps) designes og afstemmes til børn og unge, der lever med en kronisk sygdom. mHealth-apps gør det muligt for patienter at monitorere deres kroniske sygdom kontinuerligt i dagligdagen og bliver betragtet som et værdigfuldt redskab til at opnå en øget selvhåndtering af sygdom blandt patienter, en bedre målretning af sundhedsydelser til den individuelle patients behov samt større sundhedseffekter. Evidensen for at mHealth-apps kan målrettes og anvendes af pædiatriske patienter samt forbedre deres selvhåndtering af sygdom og deres generelle sygdomstilstand er dog blandet. Dette studie undersøger, hvordan mHealth-designprojekter forholder sig til specifikke omstændigheder omkring børn og unge og deres liv med kronisk sygdom.

For at undersøge hvordan mHealth-apps afstemmes i forhold til børn og unge, der lever med en kronisk sygdom, udførtes et multimetodisk etnografisk feltarbejde blandt børn og unge, der lever med hæmofili eller børnegigt, samt to mHealth-designprojekter, der målrettede deres designs mod disse to patientgrupper. Dette resulterede i empirisk materiale bestående af feltnoter om og fotografier af børn og unges hverdagsliv med kronisk sygdom samt transskriberinger af fokusgruppediskussioner blandt børn og unge, der lever med kronisk sygdom, forældre og et ungepanel af patienter på et hospital. Derudover bestod det empiriske materiale af transskriberede interviews, feltnoter, fotografier, og forskelligartet indsamlet materiale fra mHealth-projekterne. Det empiriske materiale blev analyseret ved hjælp af tematisk netværksanalyse for at udlede tematikker omkring henholdsvis børn og unges liv med kronisk sygdom og mHealth-designprocesser samt for at muliggøre analyse på tværs af disse felter.

Studiets hovedfund var, at det at afstemme mHealth-apps til børn og unge udfordres af de særlige omstændigheder der er omkring denne gruppe og deres måde at leve med kronisk sygdom på. Resultaterne viser, at der er betydelig diskrepans mellem den værdi og de formål, som mHealth-projekter tillægger deres designs, og den måde børn og unge praktiserer og oplever deres liv med kronisk sygdom på. Derudover viste studiet at de designmetoder, som mHealth-projekterne gjorde brug af, løbende svækkede mulighederne for at identificere og tage højde for børn og unge som en særlig type mHealth-app-brugere, hvilket resulterede i et endeligt fravalg af børn og unge som

målgruppe for mHealth-apps'ne til fordel for en voksen patientmålgruppe. mHealth-projekternes udfordringer med at identificere og justere designet til de særlige forhold, der gør sig gældende omkring livet med kronisk sygdom for børn og unge, var associeret med bredere strukturelle og visionære ideer om patienters muligheder for at håndtere og leve med kronisk sygdom.

Resultaterne peger på, at mHealth-innovation kan marginalisere børn og unge, der lever med kronisk sygdom, fordi designprocesserne er stærkt knyttet til patientidealer, designmetoder, og formål, der forbindes med voksne patientpopulationer. mHealth-innovation risikerer dermed, mere eller mindre uforvarende, at trække på indlejrede 'voksen-standarder' i designprocesserne, hvilket i betydelig grad begrænser, hvordan de teknologiske designs kan afstemmes til børn og unge. mHealth-projekter bør derfor være opmærksomme på de drivende kræfter, der lægges til grund for udviklingsprocesserne, fordi disse kan bevirke en marginalisering af bestemte brugergrupper. Derudover bør mHealth-innovationsfeltet undersøge, hvordan en øget opmærksomhed på og udforskning af de særlige omstændigheder, der gør sig gældende omkring børn og unges liv med kronisk sygdom og deres samfundsmæssige positioner, kan opnås i mHealth-designprocesser.

I vomit
Trauma or spontaneous?
I play practice
How are you feeling today?
I don’t know – I am not that creative – I am just opposing today
You haven’t updated your diary – do it now?
I know I’m abnormal
As well as normal
I can do the same
We don’t want it to take up too much space
I just have to go home sometimes

Poem about the field of study. Claudia Bagge-Petersen 2021.

Contents

Overview of figures, tables, and images used in the thesis:

Introduction

Mobile health smartphone applications (mHealth apps) are progressively emerging for paediatric patients that live with a chronic illness. These are apps that make it possible for patients to monitor various symptoms, triggers, treatment, and experiences of illness in their everyday lives. Within a contemporary Western patient-centred healthcare paradigm such monitoring is predicted to be valuable for improving health outcomes, increasing the patient's own illness management, and tailoring healthcare services to the patient's actual needs, while at the same time reducing healthcare expenses.

In this thesis I am interested in understanding how mobile health apps relate to children and young people. How are these apps designed and purposed, and how are they enabled to make a relationship with children and young people and their particular ways of living with chronic illness?

In this introduction, I will first sketch out the phenomenon of mHealth apps for children and young people that live with a chronic illness and describe how this phenomenon connects to a patient-centred healthcare paradigm. Second, I will state my research interest in exploring mobile health technologies' *troubled attuning* to children and young people. Third, I will introduce the empiric field of this study, that encompasses children and young people's life with chronic illness and the design processes of two mobile health apps. Fourth, I present briefly the three articles of the thesis and how they relate to the overall ambition of the thesis. Finally, I outline the contents of the thesis chapter by chapter.

Visions of patient-centred mHealth

Technological innovation in recent decades has given rise to visions of establishing more efficient and personalised healthcare systems in several countries (Meier, Fitzgerald and Smith, 2013). This vision is much driven by an urgency for dealing with the increasing healthcare costs of an ageing population that lives longer with chronic illnesses (Kierkegaard, 2013). By developing technologies for monitoring patients' relevant healthcare measures in everyday life it is expected that individual patients' needs can be exposed, and that patients' skills in responding to these needs can be improved in collaboration with healthcare professionals. In particular, the involvement of patients suffering from chronic illness in their own care is anticipated to increase both the patients' quality of life and their self-management practices, thereby enabling the individual patient to live as well as possible with illness (Meier, Fitzgerald and Smith, 2013; Bruce *et al.*, 2020). With patients' use of monitoring technologies for measuring and engaging with their own illness experiences the entirety of the patient's life becomes the object of healthcare services (Forestier *et al.*, 2019). These perspectives of involved patients and 'life with illness' have been argued to represent a paradigmatic turn towards 'patient-centred care', and against paternalistic pathological approaches to healthcare (Sullivan, 2003) in Western healthcare systems. As a continuation of its success in saving lives medicine is now increasingly about making an improved quality of life of the patients the medical goal (ibid).

In Denmark the aim of reducing costs and centring healthcare services around individuals' needs has led to an extensive digitalisation of healthcare services. Denmark has long been regarded as a world leader in deploying health-related information and communication technologies (Dobrev *et al.*, 2009; Harrell, 2009; Bhanoo, 2010; Kielstra, 2011). A contemporary account of former and ongoing public initiatives to develop digital information and monitoring technologies of patients' health counted 361 projects (MedCom, no date). Furthermore, in Denmark the digitalisation processes of healthcare are driven by a patient-centred ideology. This implies that the Danish welfare system seeks to support patients and relatives in 'taking greater ownership of their own illness in their daily lives and [enabling] them to actively participate in their own treatment' (Ministry of Health *et al.*, 2018, p. 18). Digital monitoring technologies will, according to this perspective, 'help patients to generally obtain better insight into their own illness and health data, as well as ensure a more flexible interaction with the health system also in their own home.' (ibid). Making patients collaborative partners in healthcare is, accordingly with the general paradigm shift to patient-centred care, driven by the logic of the patient being the source of information and knowledge about what he or she needs (Danish Ministry of Health, 2012). 'The voice of the citizen must be central to driving and developing our public healthcare system. It is first of all the treatment's effect on the life quality of the patient, that needs to be the point of departure for the healthcare system. […] We believe that resources of the patient should be employed in an active manner in treatment to a much greater extent – that is the wishes, knowledge, experiences, and observations of the patient.'

(Danish Regions, no date).[1] In particular, patient monitoring of various measures is assumed to enable patients to become 'actively involved', 'self-reliant' (Ministry of Health *et al.*, 2018, p. 24), and 'empowered' (Danish Ministry of Health, 2012).

The kinds of technologies that are characterised as mHealth are deemed to be an enabler of the active involvement of patients in their own care. mHealth technologies allow patient-monitoring of various health measures – for instance symptoms, treatment, abilities to engage in physical and social activities, and mood. mHealth is defined by the World Health Organization as 'medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistance, and other wireless devices' (World Health Organization, 2012, p. 6), and is emerging in the intersection between public health, medical informatics, and private business (Eysenbach, 2001). mHealth is thus a broad category of digital mobile technologies for patient-monitored information used for providing care. It should be emphasised that these technologies are not merely translations of former analogue healthcare services into some that are digital, but they individualise which healthcare issues are addressed and how. An important feature of most mHealth-technologies is namely, as stated, the patient's participation in generating, sharing, assessing, and acting on information about his or her health and well-being. These technologies thus represent something new – a new way of approaching healthcare services.

Considering digitalisation of healthcare, and hereunder technologies like mHealth, The Danish Digital Health Strategy for 2018-2022 states that 'The task is to boost digital healthcare collaboration for every patient' and '[…] seize the opportunities provided by new technology' (Ministry of Health *et al.*, 2018, pp. 3–4). In these visions of digital health technology 'for every patient' the Danish Digital Health Strategy however fails to explicate paediatric patients as a particular kind of target group for these patient-involving technologies. Yet we have already witnessed the emergence of mHealth technologies targeted at children and young people that live with chronic illness from public, private, and public-private initiatives in Denmark (MedCom, no date). These are, for instance, mHealth targeted at minors living with diabetes, asthma, pulmonary fibrosis, cystic fibrosis, cancer, juvenile idiopathic arthritis, haemophilia, inflammatory bowel disease, along with

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[1] My translation from Danish.

Tourette's syndrome, and other mental conditions (MedCom, no date). An example of mHealth for mental healthcare is Monsenso, an app, certified as a medical device, for mental healthcare delivery for a variety of patient categories, including paediatric patients, living with mental disorders. By a combination of automatically generated and patient-registered data Monsenso 'empowers' patients and enables a 'holistic view' of the patient journey (Monsenso, no date). Enabling patient-centric care by a holistic view of life with illness, and making this a point of departure for healthcare services, recurs across several Danish mHealth initiatives, including those regarding somatic illnesses of children and young people. For example, one of the mHealth app cases I will look at in this thesis is an app for managing life with juvenile idiopathic arthritis (JIA) which provides 'holistic insight' into young patient's lives with the condition for the improved self-management of their life with JIA (Daman - Digital Healthcare Partner, no date). Though mHealth technologies are emerging for children and young people in mental health fields and in non-chronic medical fields, in this thesis I will explore mHealth for paediatric somatic chronic conditions only, in order to limit the field of study.

In projects and clinical studies of mHealth the technologies' values are reasoned in multiple ways in relation to children and young people living with chronic illness. For instance, mHealth technologies are mobile, which is deemed valuable for enabling self-management activities anywhere and anytime, and for providing information about the disease course in a lived reality rather than merely on the occasions of scheduled medical consultations (Frøisland, Årsand and Skårderud, 2012; Rhee *et al.*, 2014; Fedele *et al.*, 2017). As smartphones already play a large role in children and young people's lives apps are deemed to be a suitable media for this group to attain skills in self-management of illness in their everyday lives (Robinson *et al.*, 2008; Panzera *et al.*, 2013). mHealth is furthermore envisioned to render more ownership of self-management to the children and young people themselves (Carpenter *et al.*, 2016; Fedele *et al.*, 2017) and improve their communication with healthcare professionals, along with increasing the children and young people's understanding of the illness and treatment (Frøisland, Årsand and Skårderud, 2012).

However, the evidence for mHealth technologies' abilities to integrate into the lived realities of children and young people and improve health outcomes and patient knowledge is mixed (Fedele *et al.*, 2017; Slater *et al.*, 2017). While some studies find that mHealth shows promise regarding behaviour in self-management (Fedele *et al.*, 2017) and promotion of communication, good relationships, and trust with healthcare professionals, other studies report on failure in making mHealth integrate with children and young people's everyday lives and be used by this group (Slater *et al.*, 2017). This is a point that initially motivated the study of this thesis – why is it so difficult to make mHealth technologies that are accepted by and function with children and young people living with chronic illnesses? When I started looking into concrete cases of mHealth projects with children and young people I found that some clinical trials with mHealth had even been shown to cause a worsening of symptoms for the users, compared with control groups (Rhee *et al.*, 2014; Castensøe-Seidenfaden *et al.*, 2018). This was in spite of the users perceiving an increase in control of their illness and being happy with the technologies. Yet these studies have been unable to explain the mechanisms behind these adverse effects. Furthermore, the literature in this area is characterised by mHealth being a broad and vaguely defined category. Additionally, there is inconclusiveness about the evidence in monitoring methods, technologies, and measures that can improve patients' adaptation of these technologies, their health state and life as they perceive it (Bruce *et al.*, 2020). A review by Jiang and Cameron (2020) argues that the research so far has ignored mHealth technologies' impact on patients' perceptions and experiences with illness and their management of it and how these technologies relate to patients' specific contexts. Along with a few others (e.g. Vinther, 2020) Jiang and Cameron therefore articulate a need for more diverse perspectives on the phenomenon of mHealth technologies with patients that live with chronic illness. Concerning children and young people that live with chronic illness, scholars have furthermore argued that attention to how self-management activities are established and change along with the physiological and psychological maturing of the child or young person (Schilling, Grey and Knafl, 2002) are needed to shape mHealth that responds to these existing processes (Slater *et al.*, 2017). The literature on paediatric patients' self-management has for instance argued that parental involvement is regarded as instrumental for children and young people's self-management (Ellis et al., 2007), however caregivers' roles are scarcely accounted for in studies of mHealth (Vinther, 2020). We thus know little about what characterises the making of mHealth designs that target the particular circumstances of children and young people that live with chronic illness, and the everyday life contexts that these technologies are expected to relate to in managing the illness.

Encouragingly, a growing number of significant studies within social science have attended to how digital health technologies relate to people's lives with chronic illness. Even before the advent of mHealth social study scholars raised points about how health technologies interfere with the normal flow of life for patients (Corbin and Strauss, 1985), and promote certain ways of perceiving ones' health (Mol, 2000) and relating to one's body (Oxlund, 2012), and how they emphasise patients' own responsibility and self-sufficiency (Charmaz, 2020). Regarding mHealth specifically, one ethnographic study recently attended to how such technologies' affect children and their way of living with a chronic condition and argued for a critically realistic exploration of how dimensions of everyday life of children constrain and enable use of self-management technologies (Vinther, 2020). It is such critical explorations of how mHealth is attuned to children and young people's particular realities of living with chronic illness that I will pursue in this thesis.

To summarise, we are entering an area of patient-centred approaches to healthcare services where the patient is deemed actively able to pinpoint his or her needs, aided by apps for measuring symptoms, treatment, and quality of life. The patient is thereby imagined to be assisted in collaborating with healthcare professionals to adjust treatment plans and improve his or her own skills in managing their illness in daily life – and live as well as possible with the illness. We see that so far it has been difficult to target these technologies at children and young people, with regard to getting them to use the apps, and benefit their health and quality of life outcomes, and learn more about their condition and treatment. However, we do not know why these difficulties arise. The existing literature in the field furthermore alerts us to the implications these technologies might have for this groups' perception and experience of their life with illness.

Research interest

In this thesis I aim to critically explore how mHealth technologies' approach to illness management in everyday life is attuned with children and young people's lived realities with chronic illness. The mixed evidence of use, value, and effect of mHealth with paediatric patients points to difficulty in building relations between these technologies and the lived reality of this group. Along with the fact that social science literature in the area is scarce, I identify a gap in knowledge in how these technologies come into being and encompass children and young people as a particular group of users. With this background the research question of the thesis is:

How does the creation of mHealth technologies relate to particular circumstances of children and young people and their everyday life with chronic illness?

With this question I have taken on the challenge of providing insight into how mHealth innovation projects attend and respond to the way everyday life with chronic illness is practiced and perceived by children and young people. That is, how do mHealth design processes *attune* the design to children and young people's lived reality with chronic illness? And wherein lie the *troubles* in this attuning that the mixed evidence in this area is witness to?

The subheading for the thesis reflects its key finding; there are various troubles in attuning mHealth apps to children and young people's way of living with chronic illness. By *attuning* I mean 'recognising and adjusting to a particular context', in the sense that mHealth is made adaptable to the lives of children and young people that live with chronic illness. By *troubled* I mean the aspects where it is challenging for the technology to attune to this context. Basically, *troubled attuning* will account for the struggles in designing and purposing these technologies, in relation to the particular circumstances of children and young people. By exposing the troubled attuning of mHealth I direct attention to the moments/issues/situations where mHealth does not capacitate crucial aspects of children and young people and their way of living and managing their illness, or simply overlooks these aspects. This conceptual framework will gradually be nuanced throughout the thesis, coming to also imply my ambition of troubling the ways in which mHealth innovation reflects minors as a particular group.

The phrase 'minority report' used in the title refers to my ambition of letting this thesis report on a neglected group in studies of digital health innovation. 'Minority report' is a reference to a science fiction film from 2002, originally a book, of this title. The film is about a future system – partly human, partly technological – able to predict crimes before they happen, thereby enabling prevention of those crimes. In the film, 'minority report' is the classification of occasions where the predictive system produces contradictory outputs. By these contradictory outputs the system comes to question its own functionality, and the reports are destroyed, in order to retain trust in the image of the system. In this thesis I use 'minority report' as an analogy to report on occasions where mHealth innovation as a socio-technical system produces contradictory outcomes – mixed evidence – in targeting technologies at paediatric patients. We have not yet looked closely at these contradictions and how they occur. In this thesis I therefore try to locate troubles in establishing connections between the systems' parts. How are mobile health technologies troubled in attending and attuning to children and young people that live with chronic illness?

To keep children and young people's particular socio-technical relations to their surroundings in mind I will mainly refer to them in this thesis as 'minors'. This term underlines the fact that children and young people below the age of 18 years are subject to legal, social, and structural norms that, as we shall see, come to matter in forming relations between them and mHealth technologies. Besides this, the term 'minor' is used to play with connotations of something small, less important, and immature – something to be dismissed – while at the same time 'minor', in music, is something melodiously moody – a small difference that leads to a larger impression. The thesis will account for how seemingly small circumstances of children and young people that live with a chronic illness come to play a major role in how mHealth can attune to them.

The study thereby does not attend to adaptation of final mHealth technologies with children and young people when in use. Rather, it explores mHealth in the making, its visions, and design methodologies, reflecting the way children and young people live their lives with chronic illness. The focus is on a discrete group of people in relation to the concrete design processes of mHealth technologies, and on relating this to contemporary visions of healthcare. I invite the reader to dive into the lives of children and young people that live with one of two particular chronic illnesses, namely haemophilia and juvenile idiopathic arthritis (JIA). Furthermore, I invite the reader to follow my explorations of two projects' design efforts in designing self-management apps targeted at these patient groups. Moving between realities of living with these illnesses and the designing of technologies for these realities makes it possible to critically explore mHealth's attuning to minors. Furthermore, it makes it possible to engage in more general issues concerning how technologies shape and are shaped.

Field and cases

The study of the thesis is partly based on ethnographic participatory observation with 15 minors[2] between the ages of 7-17 living with either haemophilia (n=7) or JIA (n=8) in their homes, and with their various family members (n=39 in total) across various regions of Denmark. Furthermore, the study is based on ethnographic participatory observation and analysis of the documents and materials of two mHealth projects in their aims to develop apps targeted at patients living with haemophilia and JIA. Lastly, the study is based on focus group discussions with parents (n=18) of minors living with haemophilia, minors living with haemophilia[3] (n=6), and young people diagnosed with various illnesses in a hospital youth panel (n=5). I will now introduce the groups of minors diagnosed with haemophilia or JIA, and hereafter the two mHealth projects that strived to design mHealth apps for self-management of these conditions, and that serve as case studies for this thesis.

Haemophilia is a bleeding disorder that is caused by a deficiency of a blood coagulation factor within the patient. This deficiency causes spontaneous bleeds and post-traumatic bleeds, which can lead to irreversible joint damage and lethal internal bleeds. Due to major advances in treatment, patients living with haemophilia can today, at least in many Western countries, live a seemingly 'normal' life. Their regular treatment, however, demands of the patient frequent injections (often twice per week), hospital visits, and limited engagement in some physical activities. These demands have been shown to be particularly challenging for patients that are minors (Limperg *et al.*, 2015). Not least the administration of injections can be difficult for the individual paediatric patient to learn and adjust to regularly undertaking. Research has shown that children living with haemophilia have difficulty in learning to self-manage treatment (Paradi and Hilbig, 2014) and the condition often negatively affects family life, peer relationships, and the child's experiences with school, well-being, and self-confidence (Crawford, McAlister and Immons, 2010). In Denmark it is estimated that around 200 children live with haemophilia (Bløderforeningen, 2019).

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[2] Originally 17 paediatric patients were recruited for this part of the fieldwork, which I will come back to in the methodology section of the thesis.

[3] One child living with haemophilia and his parents were participating both in the fieldwork in the homes of patients and in the focus group discussions. Otherwise, there were no overlaps of participants across the field sites.

The other diagnosis serving as a case study in this thesis is juvenile idiopathic arthritis (JIA). JIA is a group of disorders causing arthritis in children. It is an autoimmune disease that causes inflamed, swollen, stiff, and painful joints. JIA is defined as a chronic childhood condition, which 30-50% of the paediatric patients carry into adult life. However, these estimates are characterised by a great deal of uncertainty. Similarly with treatment of haemophilia, the prognosis of JIA has been considerably improved by advances in treatment, including biological therapies. Today, management of the condition is characterised by unpleasant treatment procedures, in some cases injections, and furthermore disease-related complications and medication side-effects such as eye inflammation, joint pain, and inhibited growth (Cartwright *et al.*, 2015). Research has furthermore shown negative effects of JIA on these children's quality of life by their impeded physiological, psychological, and social maturation (Venning *et al.*, 2008), and their experiences of fatigue, and school absence (Nijhof *et al.*, 2016). It is estimated that around 1,200 children live with JIA in Denmark (Gigtforeningen, 2019).

By these characteristics of the two diagnoses, I am introducing a group of minors whose everyday lives involve numerous challenges and experiences of symptoms, treatment, healthcare services, and feelings, sensations, and emotions concerning how the condition affects them and the activities in which they engage in everyday life. I primarily chose these two diagnostic cases of minors that live with chronic illness because two mHealth projects were currently targeting these groups with their designs. This would enable me to compare insights generated with the minor against insights generated with the projects. Another reason for choosing these diagnostic areas was that both illnesses demand continuous attention of minors and parents, in terms of managing symptoms and treatment, which corresponded to my interest in exploring challenges, practices, and perceptions of illness on an everyday life basis. The age span of minors that was included in the study was 7-17. This age span was chosen, given this groups' presumed abilities to express their own experiences with chronic illness and their beginning to take over responsibilities, while at the same time retaining their dependency on and close boundness to assistance by caregivers. Furthermore, I later involved a hospital youth panel where the age span was 18-25, with whom I discussed their former and present experiences in living with illness. In this thesis I do not emphasise the differences between minors of various ages within this age span. I mainly focus on the processual changes in the collaborations that characterise life with and management of illness in everyday life, without ascribing shifts in practices and perceptions to specific ages. In visiting the minors in their homes, I had the chance to observe their management of treatment and symptoms, sit with them in their rooms, and talk about their interests, daily lives, friends, toys, electronics, treatment, and parents, etc. In brief, I had the chance to explore how the challenges and experiences of their condition unfolded and how the minors themselves responded to these issues in trying to manage their lives with illness. What struck me the most in these visits was their general engagement with and interest in their own condition and treatment in a biomedical and practical sense, which is a point I will return to later in this thesis.

I will now turn to the two mHealth project cases that I followed, after fieldwork with the children and young people.

The haemophilia mHealth project was a public-private project that started in 2015. It was a collaboration between the two clinical haemophilia centres in Denmark, two regional telemedicine centres, a digital health company, and the Danish Haemophilia Society. It had the headline 'Decision supporting tool in haemophilia treatment'[4] and aimed to make a digital system for qualifying condition management decisions on a daily basis, for all haemophilia patients in Denmark, including paediatric patients. Though the design and purpose of the mHealth technology was later nuanced during development, from an early point it was decided to include an app for patients to monitor and visualise their symptoms and treatment, and a web interface for clinicians to overview these patient-reported measures. The technology was scoped to enable adjustment of the individual patient's treatment plan and improve the patient's self-management of their condition. Soon after its initiation the project further purposed to prepare a database to enable viewing of patient data for the whole population of haemophilia patients, securing a safe data-sharing environment, and making possible later implementation of a patient-reported outcome questionnaire. Besides this, a pronounced driver for the project was the expectation of lowering each patient's self-administered treatment to only the appropriate amounts, leading to a great economic saving (due to the high cost of haemophilia treatment). In this sense the project quickly came to be purposed towards much more than supporting the patient's ability to self-manage their condition in everyday life. I will later

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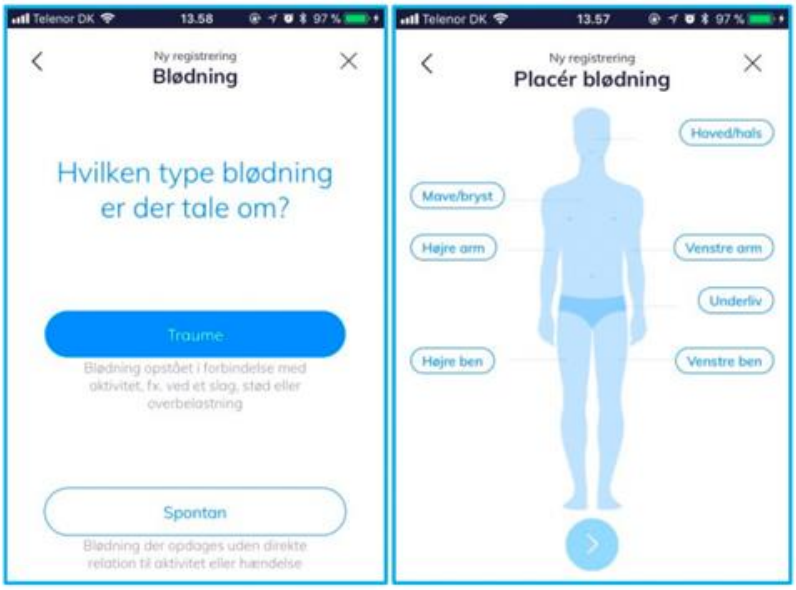
[4] This and following quotes from the projects are translated from Danish by me.

explore and analyse what this design process implied for targeting minors living with haemophilia. However, in this introduction, I wish to offer the reader a way of picturing this haemophilia project by images from the final app design.

Image 3 Screenshots of two functionalities in the haemophilia app in the final design phase. The screenshot on the left allows the user to register a bleed that has just occurred and note if it was caused by a trauma or spontaneously. The screenshot on the right allows the user to pinpoint on a body map the bodily location of the bleed.



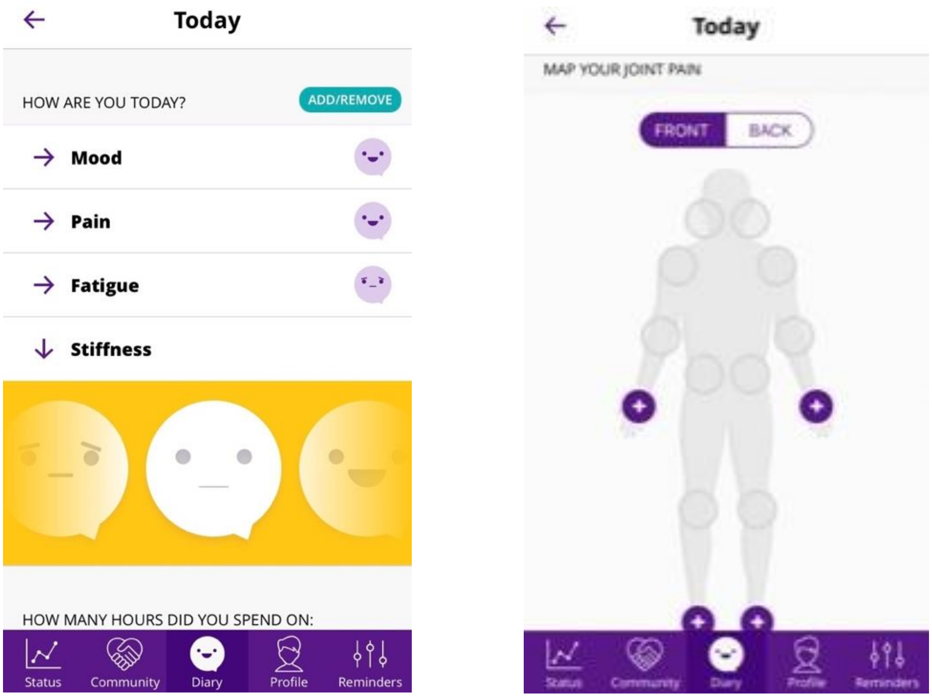
Hvilken type blødning er der tale om?

Blødning opstået i forbindelse med aktivitet, fx. ved et slag, stød eller overbelastning

Blødning der opdages uden direkte relation til aktivitet eller hændelse

The other mHealth project that serves as a case study in this thesis started back in 2013 as a partnership between a private digital health company, a rheumatologist, and the Danish patient organisation for young people living with arthritis. This project was scoped to deliver a self-monitoring app for young people living with JIA between the ages of 12-35 years, to enable insight into triggers and fluctuations of their symptoms, to help them gain greater control of their condition. In the project owners' own terms, this project had a 'holistic' approach to what it means for people to live with a chronic illness. As opposed to the haemophilia project that aimed to merely monitor symptoms, treatment, and physical activities, the arthritis project aimed to monitor a variety of everyday experiences with the patient. The project was creating a commercial app that users could bring to consultations with their rheumatologist. In the long run the project envisioned integrating the patient-monitored data with clinical databases, thereby creating research opportunities for rheumatologists and pharma companies. In one of the articles of this thesis I explore in depth how this design process, and that of the haemophilia project, proceeded, with regards to attuning the design to minors. In this introduction, however, I fast forward to the end-design of the JIA project to provide an image of what the mHealth technology came to look like.

Image 4: Screenshots of two functionalities in the final design of the JIA app. The screenshot on the left allows the user to register his or her experiences of mood, pain, fatigues, and stiffness on a scale of smileys representing various levels of daily contentment. The screenshot on the right allows for indicating the bodily location of pain.



In brief, both the mHealth projects' design approaches were articulated as 'user-driven innovation'. However, I came to gain insight into their struggles to take into consideration the children and young people's particular *position* as users, which along with minors' way of *practicing* and *perceiving* their illness is a key aspect that I will attend to in this thesis. The mHealth project cases were chosen because they included minors as a target user group, and because they were in the process of designing the apps at the time that I was able to conduct fieldwork for the study. This offered me a chance to investigate exactly what happens in terms of attuning the product to minors during design.

To summarise, I have here introduced the empirical field of minors that live with haemophilia and JIA and the two cases of mHealth projects targeting these groups, in their efforts towards making apps for improving these patients' illness self-management. These field explorations will, along with five focus group discussions, which I describe later, be the empirical foundation for exploring how mHealth is attuned to minors' life with chronic illness.

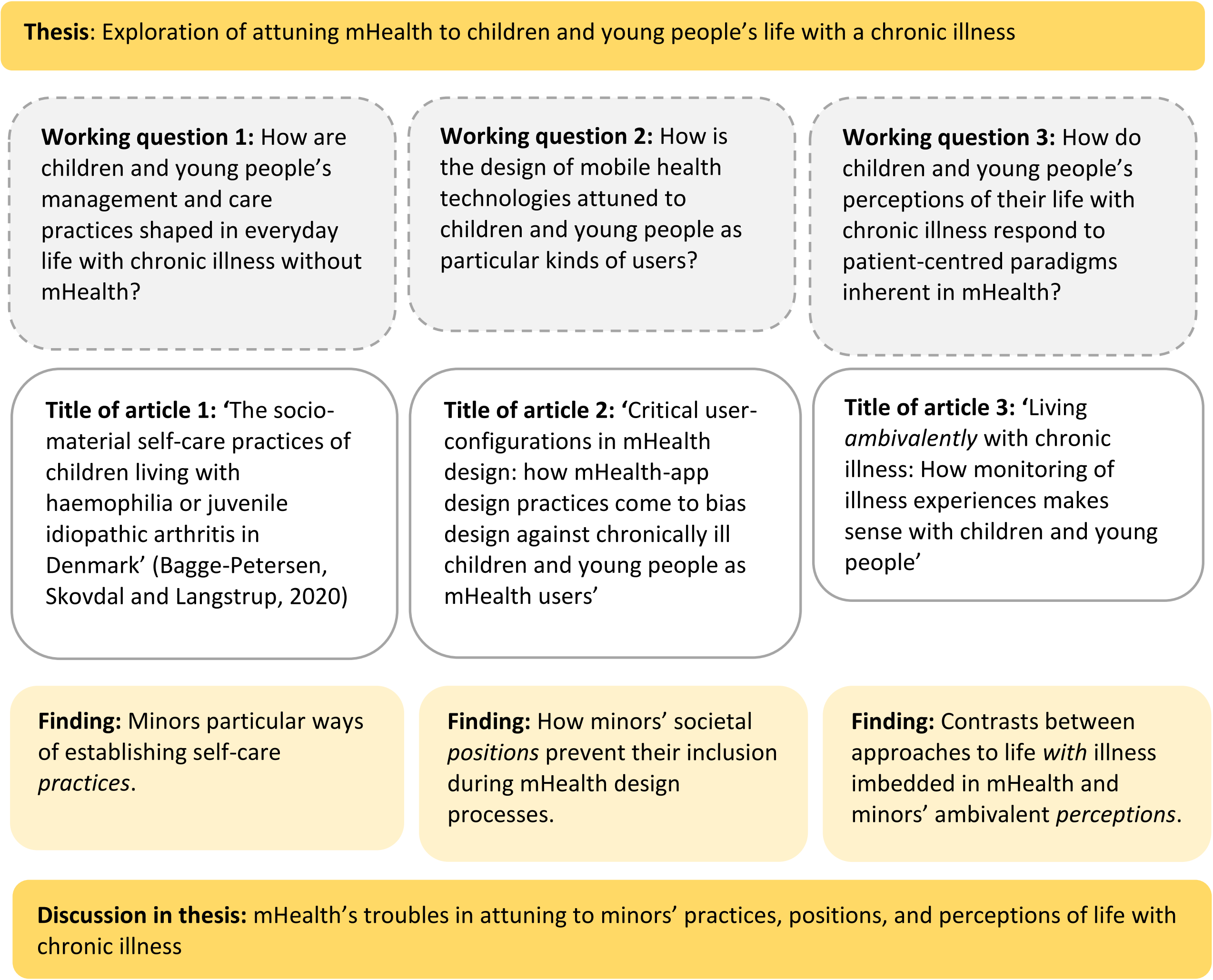
I will now outline how this empirical material prepared the ground for the three research articles of this thesis.

Relation between articles and thesis

The overall aim of the thesis is to explore mHealth's attuning to children and young people that live with chronic illness. I formed three working questions that I, through various methods, sought to explore. First, I turned to everyday life with minors living with a chronic condition to ask: How are children and young people's management and care practices shaped in everyday life with chronic illness without mHealth? Second, I turned to mHealth design processes asking: How is the design of mobile health technologies attuned to children and young people as particular kinds of users? And finally, I arranged discussion groups to explore: How do children and young people's perceptions of their life with chronic illness respond to the patient-centred paradigms inherent in mHealth?

Investigating these three questions resulted in three respective articles. Here I provide an overview of these articles, the three working questions, a summary of what each article found, and the discussion of the thesis will be. After this overview I briefly introduce each article.

Figure 1 Relations between articles and each article's contribution to an overall discussion of trouble attuning in the thesis.



Thesis: Exploration of attuning mHealth to children and young people's life with a chronic illness

Working question 1: How are children and young people's management and care practices shaped in everyday life with chronic illness without mHealth?

Working question 2: How is the design of mobile health technologies attuned to children and young people as particular kinds of users?

Working question 3: How do children and young people's perceptions of their life with chronic illness respond to patient-centred paradigms inherent in mHealth?

Title of article 1: 'The socio-material self-care practices of children living with haemophilia or juvenile idiopathic arthritis in Denmark' (Bagge-Petersen, Skovdal and Langstrup, 2020)

Title of article 2: 'Critical user-configurations in mHealth design: how mHealth-app design practices come to bias design against chronically ill children and young people as mHealth users'

Title of article 3: 'Living *ambivalently* with chronic illness: How monitoring of illness experiences makes sense with children and young people'

Finding: Minors particular ways of establishing self-care *practices*.

Finding: How minors' societal *positions* prevent their inclusion during mHealth design processes.

Finding: Contrasts between approaches to life *with* illness imbedded in mHealth and minors' ambivalent *perceptions*.

Discussion in thesis: mHealth's troubles in attuning to minors' practices, positions, and perceptions of life with chronic illness

In the first article my co-authors and I bring attention to three self-care practices in which children and young people participate to establish a response to challenges in managing their condition in everyday life. We argue that recognition of minors' ways of establishing and engaging in their own kinds of self-care *practices* might be of value for researchers and practitioners concerned with supporting this groups' agentic capabilities in illness management – including, but not limited to mHealth. In the second article my co-authors and I elucidate moments in the design process of mHealth that increasingly challenge minor patients in fitting the emerging user-profile. Both projects eventually dropped minors as a target user throughout the design processes. We argue that the design methodologies used in the projects are not mindful of the particular social and structural *positions* of minors in relation to engaging with health data. In the third article I explore with children and young people and parents their *perceptions* of life with illness, in relation to mHealth monitoring. I argue that mHealth monitoring of connectivity between the illness and lived experiences can conflict with this group's ambivalence towards illness in relation to different situations of their lives.

The articles each turn to one aspect of minors' lived realities with chronic illness; how self-management practices are established with minors; how minors are positioned in mHealth design processes, and how perceptions of life with illness are formed by minors. Thus, the articles highlight specific *practices, positions*, and *perceptions* pertinent to minors in relation to mHealth. The thesis will discuss how these particular circumstances of minors can be seen as *troubles* in the realm of digital health innovation, how this encourages reviewing the mixed evidence of mHealth for minors in a new light, and how these perspectives contribute to the field of science and technology studies.

Outline of thesis

In the first chapter, I situate the study's area of concern with minors and chronic illness, mHealth technologies, and the Danish healthcare and innovation site. In the second chapter, I outline the study's analytical framework that allows for a critical exploration of technologies' attuning to socio-material, socio-technical, and perceptual settings of certain groups of people. In the third chapter, I present my methodology and ethical reflections in researching technology in its development and relation to the lived reality of minors. In the fourth chapter, I present my empirical data and analytical process. In the fifth chapter, I present my results and discuss them, while also reflecting on how the study gives rise to new perspectives on digital health innovation as well as to the scholarly field of science and technology studies. Lastly, I conclude the thesis by revisiting my research question and the broader perspectives for attuning mHealth to minors' lived realities.

1. Minors, chronic illness, and mHealth

We'd like to know a little bit about you for our files
We'd like to help you learn to help yourself
Look around you all you see are sympathetic eyes
Stroll around the grounds until you feel at home

Verse from the song 'Mrs. Robinson' by Simon and Garfunkel, 1968.

It is estimated that 10% of adolescents suffer from a chronic illness that affects their daily lives (Suris, Michaud and Viner, 2004). Various research fields have attended to different aspects of minors' lives with chronic illness, both in terms of their physical health and psychosocial well-being, and their illness management. In the following paragraph, I will introduce the reader to these fields of knowledge, and paint a picture of what it implies for minors to live with chronic illness. Following this, I will present the insights we have gained about mHealth technologies that are emerging from minors. Along with these outlines of the literature, I will show how minors are repeatedly viewed from adult perspectives. The terms used in this area are mainly developed by adults and applied to minors. Furthermore, I will show how minors' relationships with their illness are seen in light of barriers against, and possibilities for, moving them into specific adult-like norms of adherence, behaviour, and health outcomes.

My intention with this presentation of the literature is thus to convey knowledge of what it means to be a minor with a chronic illness, how mHealth is emerging for this group, and explore the tendency towards viewing minors as 'becoming' adult-like patients. Thereby I, along with other researchers, depict a neglect, in health informatics and paediatric literature, of staying with minors' 'being' in life with their illness in its own right.

Minors who live with chronic illness

Scholars of the sociology of health and illness have argued that children and young people's health became of particular concern within a 20th century surveillance medicine paradigm. This paradigm used monitoring of normal populations to serve as a framework for determining illness (Armstrong, 1995). The concern with minors mainly evolved around how to improve health and detect illness, triggers, and social determinants (Brady, Lowe and Olin Lauritzen, 2015). Mayall (1998) argued from a sociological perspective that children were regarded as objects of state policy because of their future citizen status, which instigated a preoccupation with children's body size, behaviour, and development. This preoccupation has furthermore been shown to be reflected in preventive medicine and health promotion programmes directed at children and their parents (Brady, Lowe and Olin Lauritzen, 2015). These health promotion programmes instigated categories of children as heathy or ill, and normal or deviant. Researchers have shown that such normative categories still account for the shaping of children and young people's experiences of themselves and their lives today (ibid). Also, these categories increase parents' awareness of risks and considerations of how to support the well-being of their children in physical, mental, and social aspects of life. 'Deviance from perceived norms becomes a matter of concern and of intervention' in both medical health aspects and in how life is lived (ibid, p. 177). This point, made in the sociology of health and illness, resonates with the childhood literature that similarly finds that children who deviate from so-called 'normal' childhood are pathologised and become subject to intervention (Skovdal, 2012).

Thus, ever since the inclusion of children and young people in health policy, their coming of age and the value of their normality, health, and contributing abilities as citizens have been a dominant focus in healthcare. From a sociological point of view, scholars have further accounted for how the measuring of minors' minds and bodies has largely been done from an adult perspective (Brady, Lowe and Olin Lauritzen, 2015). Children and young people are not always included in making decisions about their own care, and scholars have shown how parents and healthcare professionals often reframe or dismiss children's experiences and bodily sensations within healthcare, to fit the applicable frameworks for understanding health and responding to illness (Carter, 2002). Bergnehr and Nelson (Bergnehr and Zetterqvist Nelson, 2015) in a sociological study of Nordic health policy, show that children and young people today are still largely assumed to be passive and shaped by adults, and that their health is reviewed in an individualistic and decontextualised manner.

Such issues have provoked calls for exploring children and young people's experiences of and capacities for interacting with health practices (Brady, Lowe and Olin Lauritzen, 2015). The argument is that we cannot fully understand illness' impact on children and young people's lives without accounting for their understandings, experiences, competences, and agency in these matters (Mayall, 1998). We should therefore attend to how children and young people differ from adults, when considering the design of healthcare services and spaces, scholars argue (Birch, Curtis and James, 2007). This would help us to see how a minor's experiences have implications for how their illness unfolds in everyday life and how this could be supported for them to reach their best possible health state. Furthermore, I argue that it would be interesting in itself to explore minors' experiences, understandings, and practices in their own lives with illness, and their relationship to illness management interventions, in order to enable insight into how these lived realities are considered in mHealth innovation.

The attention to psychosocial dimensions of minors that live with chronic illness

I now turn to how recognition of minors' experience of illness and its impact on health state and well-being travel outside the sociological and psychosocial realm, and yet also become an object of comparison to normality.

Stimulated by an increased attention to the sociology of childhood (James and Prout, 2015) interest has grown in researching children's own experiences and roles in the management of illness and health over the past decades (Brady, Lowe and Olin Lauritzen, 2015). This is witnessed by a growing number of psychosocial studies of minors' perspectives on the impact of illness and health in their lives. Furthermore, this research interest also feeds into the fields of health informatics and the paediatrics literature, where it is increasingly acknowledged that chronic illness can disrupt children and adolescents' development in several aspects beyond the biomedical. In the fields of health informatics and paediatrics there is an emergent acceptance that physical symptoms, daily treatment, hospitalisation, and frequent consultations with healthcare professionals can interfere with the minor's everyday life (Shaw *et al.*, 2010). The psychosocial literature has furthermore shown that the amount of energy and time that symptoms and treatment require can reduce the minor's dedication to interactions with peers and other social relations (Reiter-Purtill, Waller and Noll, 2009). Also, Barlow and Ellard (2006) have demonstrated in a review how significant psychosocial distress from the burden of illness often affects the minor and family. Another review shows that distress related to parenting a child with a chronic illness is significantly higher than for parents of healthy children and is especially associated with responsibility for managing treatment (Cousino and Hazen, 2013). Difficulty can also evolve around the relations between parents and their children, involving how to delegate responsibility and tackle risks and challenges in everyday life with the condition. For instance, Beeton et al. (2007) shows through interviews and focus groups that parents of children living with haemophilia are affected by how well their children are managing the condition and the difficulties that their children experience.

The psychosocial attention has ensured that success in children and young people's life with illness is increasingly evaluated in terms of minors' resilience to stressors, and their achievement of a childhood and quality of life that is comparable with population norms and healthy peers (Hamall *et al.*, 2014). However, it is important to note that this attention to minors' psychosocial well-being and everyday life is again preparing the ground for comparison to a normal and healthy population. Furthermore, these comparisons then lay the foundation for interventions of improvement, as I will show in the following outline of the literature.

'Transition' of minors that live with chronic illness

Much paediatric and health informatics literature evolves around 'transition', which covers the process of patients moving from paediatric healthcare services to adult services. I now outline the literature on the challenges that arise for minors in transition and how transition interventions, with increased concern for the psychosocial dimensions of minors' lives, seek to improve their responsibilisation in condition management. I draw attention to how the focus on transition interventions often reflects adult patient capabilities, focusing on minors' *becoming*, and sees minors' present being in terms of barriers for transition.

The transition literature evidences paediatric patients' neglect of treatment management and the deterioration of their health as they move into adolescence, and shows that this group experience multiple challenges concerning medical, psychosocial, and educational issues that need to be addressed (Howsley *et al.*, 2018). For instance, treatment adherence has been shown to decline among minors that live with haemophilia when they enter adolescence. This decline has been explained by the young people's focus on short-term goals in treatment and their neglect of regular (long-term) treatment, which problematically increases the risk of long-term joint damage (Petrini and Seuser, 2009). For young JIA patients, transition has similarly been shown to imply decrease in illness management, deterioration in health (Howsley *et al.*, 2018), and increased exposure to depression, anxiety, and social withdrawal, compared to healthy peers (LeBovidge, Lavigne and

Miller, 2005), and suboptimal quality of life due to pain and functional disability (Cartwright *et al.*, 2015). The offering of differentiated healthcare services between different age groups naturally depends on individual healthcare systems in different countries. In Denmark there is a differentiation between paediatric and adult healthcare services and a great focus on how to improve the transition for young patients. The actual shift from paediatric to adult healthcare services happens at around the age of 18 in Denmark. However, within the social science of adolescent patients, it is being argued that the transition process should start at around the age of 9 (Hanghøj, 2016), with early steps of patient takeover of responsibility for illness management and communication with healthcare professionals at an even earlier age (Beacham and Deatrick, 2015).

With the rise of attention to minors' experiences with chronic illness, transition interventions have aimed to position children and young people as active subjects, listen to their opinions, and account for their social context, in order to increase their health and psychosocial well-being (Bergnehr and Zetterqvist Nelson, 2015). Reviews of young people's own experiences of chronic illness in adolescence show that their life with chronic illness is especially characterised by feeling uncomfortable in their own body and in the world (Venning *et al.*, 2008), aversion to being different, stigmatised and misunderstood, uncertainty about their condition and how to manage treatment, and by a striving for normality (Tong *et al.*, 2012). Concerning normality, young people's identity formation has been shown to influence their treatment adherence and longing for detachment from caregivers, as they try to be like healthy peers (Suris, Michaud and Viner, 2004). In the Danish context it has further been argued that chronically ill adolescents' identities are constructed in terms of balancing normality and marginality (Hanghøj *et al.*, 2016). Normality is linked to youth while marginal identity is linked to illness. The young people balance these identities accordingly with settings outside the home, where they perform their youth identity, and in the home setting, where they attend to the illness (ibid), which is a point that I will return to later as my study confirms this. Also, health professionals' skills in youth-friendly, respectful, trustworthy, and confidential communication have been shown to influence young people's treatment adherence (ibid).

As the literature is increasingly recognising the psychological and psychosocial dimensions of transition, the minor's own role and responsibility in managing his or her illness is increasingly regarded as the key issue of concern. 'Condition self-management' refers to efforts in managing the condition in everyday life (Beacham and Deatrick, 2015) and often implies reacting to symptoms, managing treatment, and communicating with healthcare professionals. However, it also often implies adapting lifestyle and everyday activities to the condition, symptoms, and treatment. Interventions for increasing self-management among paediatric patients aim to consider the young person's preparation to take over responsibility, while at the same time accommodating his or her general transition into young adulthood and their specific needs and circumstances (Hanghøj, 2016). Within the field of adolescent health, Hanghøj and Boisen (2014) conducted a review to draw attention to minors' own self-reported barriers to medication adherence in Denmark. This review reported on several aspects that adolescents themselves perceived as crucial for their takeover of responsibility for adherence to treatment. These include the young people's relations with peers, parents, and health professionals, their striving for normality and freedom, their experience of how their treatment affects them physically and mentally, their forgetfulness, their problems in integrating treatment into their daily lives, their troubles in dealing with complexity of treatment, and to some extent the financial cost of treatment (ibid). There is, as yet, little evidence for how to support these needs with successful interventions. Making the transition easier for the patient, securing an optimal health state and psychosocial outcome for issues such as anxiety and finding social support, remains challenging (ibid). Furthermore, it is still difficult to determine patients' readiness to transition to adult healthcare services (Howsley *et al.*, 2018).

What I especially find interesting in the transition literature is its focus on minors as becoming adults and its attention to the barriers to achieving this. The term 'transition' acknowledges the changes that happen to all minors that grow into adolescence, and the literature describes purposes of moving this group towards responsibility, autonomy, and individuality. The attention given to developing initiatives that support adolescents in the challenging move into adult healthcare services is certainly a sign of progress. However, it seems to happen at the expense of developing a discourse that can account for this group's 'being' with their illness. By 'being' I draw attention to the present situations of the minors' abilities, involvements, practices, norms, values, and perceptions in their lives with chronic illness. The interventions account for the minors in terms of what goals they ought to achieve and what barriers their present situation represents. Furthermore, when the literature discusses the younger children, it is by accounts of parents' experiences of their children and their children's behaviour (Stewart *et al.*, 1981; van Dulmen, 1998; Carter, 2002) and not by accounts of the experiences of the children themselves.

Minors' agency in their lives with illness

Driven by identification of the limited attention to what minors themselves do, want, and need, scholars have argued for also attending to minors' agency. In this emerging body of literature focus is given to how particular social and cultural contexts are decisive for minors' lived experiences (Brady, Lowe and Olin Lauritzen, 2015). For instance, Sawyer (2003) shows that children and young people are not merely passive or conforming but develop strategies to deal with or sometimes oppose adult-defined agendas. Furthermore, Ye et al. (2014) show how minors can sometimes obtain skills and strengths beyond what is considered normal for healthy peers because of their illness experiences. This means that some children and young people can thrive despite of (or because of?) their illness, and paediatric patients are not predestined to experience impaired development or a negatively affected everyday life (Lum, 2017).

By this attention to agency, social science scholars hope to imply a shift from seeing children as immature and 'becoming' adults, and towards seeing them as competent 'beings' and towards identification of their own possibilities to act (James and Prout, 2015), their rights, and the structures that restrict or enable their control over their lives (Alanen and Mayall, 2002). Children must be understood as social agents and co-constructors of their own realities, and in terms of how their agency is enabled and restrained in specific settings of power and participation (Brady, Lowe and Olin Lauritzen, 2015). We see that rather than looking at transition, this field of literature thus attends more to applicable norms and structures of childhood and chronic illness, and their being within these contexts. In this area, some scholars have furthermore argued for recognising children as a social minority group. Also, it is stressed within this literature that there is variation and diversity among children, considering for instance age, gender, capacity, ethnicity, national and cultural contexts, but also within one child's life (ibid). We must identify minors' placement, and how it is structured in society in relation to other groups. This involves how children are taken account of, listened to, and empowered in various social settings and healthcare, and the way discourses and imaginations of children appear in health policy and interventions (ibid). Michaud, Suris, and Viner (2007) have in this regard shown how children are not included; that management decisions are generally made in an adult-to-adult manner between health professionals and parents, and that on a day-to-day basis disease management is undertaken directly by parents.

The social sciences’ notice of minors’ uninvolvement and diminished capabilities have resulted in calls for greater inclusion of paediatric patients in consultations, to make them comfortable in speaking with healthcare providers from a much younger age, possibly as young as the age of 4 (Beacham and Deatrick, 2015). Furthermore, there are calls for including paediatric patients in goalsetting, in creating strategies to meet these goals, and in evaluating outcomes reflectively, to allow minors to develop appropriate skills for making decisions when entering adolescence and young adulthood (ibid). Positively, there is thus ambition to care for and support minors in their hardships with becoming independent in managing their conditions and thriving in their lives with illness. We see how accounts of children and young people’s experiences are informing new interventions to support their active engagement with and participation in management of their conditions. Looking at minors’ becoming, and supporting improvement of their skills, are valuable in terms of their making a more seamless transition. On the other hand, this implies an emphasis on what minors are yet incapable of, and leaves little room for getting to know their experiences, values and practices, independently of what kinds of patients they are supposed to become. This preoccupation with fitting the minor into a healthcare system geared towards adults prevents questioning of how the healthcare system reproduces ideas of the passive child, the coming into being adolescent, and the responsible adult patient, while these characteristics might be much more fluent and contextual across the age groups.

To summarise, much literature on children and young people that live with chronic illness revolves around challenges and health risks in their transition to adult healthcare and their takeover of responsibility for condition management. A growing literature highlights minors’ contexts of social relations and agency. Psychosocial and contextual dimensions of living with a chronic illness thus increasingly supplement a focus on medical adherence and compliance within this group. Though such insights have prepared the ground for attempts to support minors in overcoming challenges to better transition into adult healthcare services, and for improving their learning, responsibility, and condition management practices, it still fails to acknowledge minors’ agency and the evaluation of interventions. Thereby the insights gained do not arise from the grounds of their actual living or with their input. Little language is developed to account for the minors' living with and managing of chronic illness in its own regard – their being with the illness.

I now turn to how mHealth is deemed to be a way of supporting minors in improving their condition management. I begin by giving an account of what mHealth is and then move on to scholarly considerations of mHealth in relation to the approaches outlined above to minors and chronic illness.

mHealth with minors

There is in general little consensus on how to define mHealth. It emerges out of the broader category of eHealth that is also defined in multiple ways (Meier, Fitzgerald and Smith, 2013). The most commonly used description of eHealth is provided by Eysenbach (2001), who terms it an emerging field of internet-based technologies of health services and information that intersects medical informatics, public health, and business. The discourse about enabling a more efficient and patient-centred healthcare system through digital health technologies, presented in the Introduction, is echoed in the field of eHealth; eHealth technologies are imagined to ´improve the continuity of healthcare information flow, [to] facilitate the re-engineering of care processes so that they become much more patient-owned and patient-controlled, and [to] enable better ways of accessing and producing care.' (Geissbühler, 2012, p. 1). *m*Health is a group of technologies within the broader eHealth category. mHealth is, roughly speaking, 'the practices of medicine and public health with support from mobile devices' (Meier, Fitzgerald and Smith, 2013, p. 362), and again patient-owned and controlled. Often mHealth is designed as a smartphone app to provide health services and information. mHealth technologies seek to support healthcare information sharing between healthcare professionals, patients, and professionals, by monitoring patients' health in real time (Germanakos, Mourlas and Samaras, 2005). Today, the monitoring is often carried out by the patient manually entering information but it can also be automatically transferred, for instance via biosensor monitoring devices (Meier, Fitzgerald and Smith, 2013). The aim of mHealth is often to improve mood and behaviour along with the health state of the chronically ill patient (Cipresso *et al.*, 2012). The variety of approaches that mHealth technologies take towards these aims range from 'biomedical', with monitoring of 'objective' measures of the illness, to more 'holistic', with monitoring of 'subjective' experiences of how life is perceived by the patient. For instance, the haemophilia app case study of this thesis merely monitors symptoms, treatment, and physical triggers, whereas the JIA app furthermore monitors the emotional and bodily experiences of how it is to live with the condition.

Patient-centred health care and measuring patient experiences of illness

As the patient-centred healthcare paradigm acknowledges that life with illness implies a profound impact on all aspects of patients' lives, the 'patient experience' is increasingly assessed by technological tools like mHealth (Bruce *et al.*, 2020). Often, patient experiences are accounted for via Patient Reported Measure (PRM) (in other instances 'patient reported outcome measures' (PRO or PROM)) implemented in mHealth. PRM accounts for how illness, care, and treatment impact the entirety of a patients' life (Forestier *et al.*, 2019). In concrete terms, PRM measures often implies patients' monitoring of their health-related quality of life, quality of life, symptoms, functional status, feelings about illness, and experience of treatment and healthcare (ibid). The frequency of and extent to which PRM are implemented differs between mHealth-technologies and diagnostic cases. Most of the mHealth technologies for minors that I have encountered either implement a PRM-questionnaire with a frequency of 3-12 months or implement a selection of the PRM-measures in the apps for daily or weekly monitoring. For instance, the JIA app included patient reported measures of mood, fatigue, joint stiffness, and pain for daily monitoring, whereas the haemophilia app project considered including an annual patient-related outcome questionnaire in the app. The issue to notice here is that patients are to monitor various aspects of their lives that *might* relate to their illness, besides measuring treatment and symptoms characteristic for their diagnosis. In addition to technologies that measures biomedical values of patients' diseased bodies (for instance the blood glucose monitor) mHealth technologies then also rely on the first person perspective and experience, that is the patient's self-reported experiences of symptoms, triggers, and treatment administration (Bruce *et al.*, 2020). As with my two empirical mHealth project cases, it is patient registered experiences of the illness that are monitored with the mHealth technologies. Therefore, it is 'illness' as experienced by the patient that is of concern in mHealth monitoring, as opposed to 'disease' which accounts for a third person (healthcare professional's) perspective on and investigation of the patients' health (Carel, 2017).

mHealth technologies with minors

mHealth is increasingly employed to assist condition management for minors that live with chronic illness. Seen in a historical perspective, childhood in the 21st century has seen an increasing amount of technology in the settings of home, school, and play spaces (Anderson *et al.*, 2009). Technology with children and young people has in general implied both sceptical and optimistic views regarding this group's relationships to the internet, smartphones, computer games and online social networks. The concerned voices attend to children and young people as victims of consumerism, regarding safety, privacy, and age-appropriateness (Bogost, 2008; Gee, 2008). The positive voices highlight the possibilities of enabling this group to express themselves in various situations (Anderson *et al.*, 2009). Interest in the relationship between minors and digital technologies is also starting to emerge in regards to how digital health technologies can be both subjects of concern and of potential benefit to minors. For instance, a Lancet Financial Times Commission entitled 'Growing up in a digital world: Governing health futures 2030' was recently formed to explore how frontier health technologies, such as Artificial Intelligence and eHealth, can improve 'the health and well-being of children and young people in an ever more digital world' (The Lancet & Financial Times Commission, no date)'. This commission attends to political, ethical, and human rights perspectives to ensure worldwide governance models in this area, and stress the importance of including youth voices in the accelerating digitisation of healthcare (ibid). Within the field of mHealth innovation, there is in general an optimistic, perhaps an opportunistic, atmosphere around the widespread ownership of smartphones and access to the internet among children and young people. Developing apps for devices that are already integrated with their everyday life is imagined to be a convenient way to engage paediatric patients in learning about and managing their chronic illness (Huda *et al.*, 2017). As a reaction to this optimism social science scholars have called for nuances to mHealth's opportunities. Whereas the anytime-anywhere discourse is deemed supportive for organising individuals' daily activities, autonomy, preferences, and unique situation (vanden Abeele, de Wolf and Ling, 2018), these technologies also structure people's lives, and bring norms of greater responsibility for the individual's own health situation, for managing correctly, and for integrating technologies into everyday life, these voices argue (Shin and Holtz, 2020).

Attending to minors' 'self-management' of chronic illness

Common to various mHealth technologies is the ambition to improve condition 'self-management' via patient monitoring. Chronic illness self-management is widely applied to contemporary healthcare services (Lorig and Holman, 2003) and the term is used interchangeably with 'self-care', 'self-monitoring', 'self-tracking', 'self-recoding', 'symptom-management' (Schilling, Grey and Knafl, 2002; Minet *et al.*, 2010; Jiang and Cameron, 2020), and 'patient empowerment' (El-Gayar *et al.*, 2013). These terms have followed the turn to patient-centred healthcare and digital health technologies; however, they are often vaguely defined. Self-management can imply that the patient will take responsibility for the illness, have an active role in care, or simply manage their treatment and symptoms. Furthermore, I see disagreement around who is imagined to be carrying out the self-management; is it an individual patient activity (Badawy *et al.*, 2018), or partly taken on by family (Wysocki and Greco, 1997), by a community (Dadgar and Joshi, 2018), or by healthcare professionals (Archer *et al.*, 2014), or a mixture of these?

Within the field of sociology, Corbin and Strauss (1985) famously encouraged attention to self-management in healthcare with chronic patients, arguing that patients always in some way manage. Later, Lorig (2002) elaborated on this, stating that patients are not merely consumers but also producers of care. These perspectives have given rise to ideas about 'expert patients', and to the aim of supporting people's confidence in their existing practices of illness management through goal setting and the mastering of new skills (Lorig and Holman, 2003). Among other scholars, Bury (2016), in response to this, has critically argued how such perspectives instigate norms of what patients ought to do in terms of managing their condition and of becoming expert patients. This argument is similar to the one I noted in a paragraph above, that the identification of minor patients' agentic capabilities and their coming of age turn the focus onto how they ought to acquire almost adult-like responsibilities and skills to manage their condition.

The discourse of self-management, empowerment, and similar prescriptive notions are today part and parcel of mHealth with minors (Kerner and Goodyear, 2017). A review demonstrates that 'empowerment' is a widely used term in relation to children's participation in design and use of digital technologies (van Mechelen *et al.*, 2021). This review shows that empowerment recently came to mean making children and young people capable of creating the changes they need, changing their environment, but also coping with their present situation. The term 'empowerment' thus implies making the minor capable of taking greater control over their situation. It both accounts for how to make minors part of design processes, and how to enable minors to engage with their illness, though it is rather vague about what exactly this implies. In the two mHealth project cases of this thesis the terms 'empowerment' and 'self-management' are used as a framework for what the technologies aim to do for the user: the JIA app seeks to empower young people living with JIA and the haemophilia app seeks to improve patients' self-management. The development of health management technologies has, when targeting young users, adopted a self-improvement framework, which implies a behavioural change imperative for the young user (Kerner and Goodyear, 2017). mHealth represents the idea that patients want to and are capable of being directors of their own lives with illness and that they just need the right tools to voice their needs for specific healthcare services, become empowered, and self-manage their condition. Monitoring their own activity or health data should increase their motivation to make progress; and achieving a better health state, evidenced by numbers, would be seen as a sufficient reward to for them to keep making progress (ibid). However, the current scholarship of self-monitoring and management of peoples' health seriously limits unfolding how minors relate to these empowerment technologies (Freeman and Neff, 2021).

Involving minors in mHealth design

Whereas we see a 'one-size-fits-all' tendency in self-management and empowerment technologies with minors (Freeman and Neff, 2021), many mHealth projects try to be attentive to including minors' perspectives in the design process. Participatory design techniques are widespread and proclaimed to be valuable in digital health development (Kushniruk and Nøhr, 2016). Involvement of patients is imagined to be providing a safeguard to ensure that the final design will fit the patient's perspectives and enable them to take action in managing their condition. The participatory techniques can vary in how and to what extent patients are involved and can be associated with design approaches such as user-driven design, user-centred design, and co-creation.

While research has pointed to a subordination of minors' experiences to aims prescribed by adults within digital health innovation, this has encouraged a turn towards design methods that can reflect minors' voices and values (Potapov and Marshall, 2020). The intention behind involving minors in digital design is that the privilege of perspective should not merely be attributed to parents, and that an effort should be made to elevate minors' agency in affecting design processes that are constituted by multiple stakeholders and value propositions (Druin, 2002). Participatory approaches are intended to offer children and young people an engaging role that, rather than placing them as mere consumers of technology, affords them roles as testers, evaluators, co-designers, and co-investigators (Druin, 2002; Meyers, Fisher and Marcoux, 2007). The important thing, according to these scholars, is to find ways to 'empower' young people in the design process (Potapov and Marshall, 2020). This is expected to produce solutions that meet minors' needs and that they will adopt and use for improving their self-management. However, as I will argue later in the thesis, placing minors at the centre of design and making them capable of partaking in the development process does not alone ensure successful designs.

While there are these efforts in involving children and young people in mHealth design, offering them a voice, and being attentive to their agency, we do however still see hardships in making final mHealth technologies succeed in various aspects. As outlined in the introduction there is mixed evidence for how mHealth improves the health state, condition management and quality of life, for minors living with chronic illness, and for how it can be integrated into minors' lives (Fedele *et al.*, 2017; Slater *et al.*, 2017). A systematic review from 2009 showed early evidence of improvement of symptoms in children and young people with health conditions using internet-based self-management interventions. In this review there was, on the other hand, conflicting evidence regarding improving young patients' knowledge about their condition and quality of life (Stinson *et al.*, 2009). Simultaneously improving both health state and quality of life seems challenging for mHealth technologies. Furthermore, reviews of mHealth technologies for specific diagnoses can show positive results in improving health states, while individual projects can show the opposite. A review of digital health technologies for school age children and adolescents living with type 1 diabetes showed a positive increase in glycaemic control (Guljas *et al.*, 2014), whereas an individual clinical study has, as mentioned earlier, shown adverse effects on glycaemic control with mHealth (Castensøe-Seidenfaden *et al.*, 2018). Whether these different outcomes are associated with the media used, the features, the design approach, or the way the technologies are orchestrated within a context of delegation of responsibilities, or something else, remains an unsettled issue. The literature on mHealth with minors is for instance unclear about distribution of practices and responsibility between actors using the mHealth technologies (Fedele *et al.*, 2017; Armoiry *et al.*, 2018). Most research in the area does not study parents as part of disease management activities (Gibson *et al.*, 2010; Rhee *et al.*, 2014; Carpenter *et al.*, 2016). However, in studies where the target group is very young, around the age of 5 and below, it is only the parents that are involved, and not the children (Fedele *et al.*, 2017). Lastly, a persistent issue is that most mHealth interventions fail to be fully integrated into real world settings (Majeed-Ariss *et al.*, 2015; Ossebaard and van Gemert-Pijnen, 2016). Scholars have therefore called for high-quality evidence on development, evaluation, use, and effectiveness of mHealth for minors (Majeed-Ariss *et al.*, 2015) that should provide further evidence for how the technologies relate to the context of the minors' real world setting. An important contribution to the understanding of how mHealth relates to minors has however recently been offered by Vinther (2020). Her study coincidentally was also carried out in the Danish context and concerned children suffering from JIA[5]. Vinther's study importantly directed attention to the children's use of and relationship with a specific mHealth app for improving condition management. The study showed that the children changed their experiences of themselves, which was not always beneficial to their illness self-management, which heightened their experience of being a patient.

Various scholars have hypothesised as to why centring the design around the minors via participatory design processes does not produce efficient and useful mHealth technologies. Within the field of design with children, Shin and Holtz (2020) argue that involvement of children and their parents in design processes is often limited to a single design activity or interview, which is not enough to secure the patients' perspectives throughout the design process. Shin and Holtz also draw attention to how projects primarily capture parents' observations of the children's practices, perceptions, and barriers in living with and managing their condition. Furthermore, we see examples

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[5] The scholar Katrine Stampe Vinther, who carried out this study for her PhD thesis, was at Aarhus University, Denmark, during her scholarship. We had no knowledge about each other's projects until she stumbled upon my research description on LinkedIn and reached out to me during my own study. Our projects can be seen in a complimentary perspective. Whereas Vinther's thesis centres around a JIA mHealth app *in use* and exposes unintended effects of the technology on the paediatric patients' self-management activities and perceptions of themselves and their lives, my thesis centres around how such apps *come into being* and how they are *prepared* to relate to the particular circumstances of paediatric patients. With Vinther's contribution my thesis has a unique opportunity of linking its findings on mHealth's troubles in attuning to paediatric patients while an app is in development, to how a similar mHealth app related to paediatric JIA patients when in use.

of projects that strive to build the design on minors' experiences yet fail to recognize everyday life schedules. These schedules can act as barriers for health monitoring in certain situations in the children and young people's lives, particularly when they are at school (American Diabetes Association, 2014; Shin and Holtz, 2019). For instance, school phone policies, or activities that happen outside the routine, such as athletics or school clubs, are rarely revealed by the study methods which focus on parents' perspectives (Shin and Holtz, 2020), which could explain some of the lack of minors' adoption of mHealth. This has caused scholars to call for increased active involvement of children and young people in the design process, to account for daily routines, perceived benefits, and obstacles in using these technologies, which will generate unique insights for the design interventions (Stålberg *et al.*, 2016). These points about limitation of involvement of minors, the parental/adult 'speaking over' of minors' perspectives, and the neglect of certain contexts and situations, are issues I explore in more detail in this thesis.

Others have pointed to the fact that even though children and young people are placed as the crucial voice in design processes, and the design accommodates their articulated needs and perspectives, designs can still fail (Smith *et al.*, 2014). A study shows that just because children and young people use mobile technologies, such as text messaging, and express the view that it would be acceptable to use this medium for health management intervention, this does not mean that they will actually use it (ibid). What children and young people say they want can conflict with their actual experience and practices with the final technology. Other scholars have added to this insight by stating that qualitative design approaches, such as semi-structured interviews, workshops, and observations, also have their weaknesses in a lack of ability to encompass children's perspectives (Poole and Peyton, 2013). Here, children's inability to account for themselves has been voiced as a barrier to designing technologies that have an active long-term usage (which can naturally also be true for adults). Many studies therefore return to relying on 'parents as the main research participant, while children [serve] as minor actors in the research processes.' (Shin and Holtz, 2020, p. 2). It should be noted that researchers within design studies are arguing for child-adapted methods, such as design probes and gamification appropriate to the children's ages, to seek out their perspectives and experiences (Tsvyatkova and Storni, 2014). However, these are not, to my knowledge, design methods extensively applied to designing mHealth technologies.

While I echo Poole and Peyton (2013) in their call for developing methodologies that transcend what minors can convey from their own lives in technological design processes, I see a need to reconsider what a child-centred approach should encompass. This is because a child-centred approach, in its efforts to give minors a voice, and account for their capabilities and values, might miss recognising that digital technologies are intended not only to work with an individual but within a socio-material assemblage of actors. I will return to this point after a final note and a summary of the literature outlined above.

A critical note on adultism and participation in mHealth

What is important for me to emphasise about the literature reviewed above is how minors' experiences are often accounted for through parents; that minors are prepared, from an increasingly younger age, to take responsibility for self-managing their condition; that their participation in designing interventions often neglects their specific context, their inability to account for their daily lives, and that their perspectives are often spoken over by adults. Children and young people are dependent on adults in their lives, and it makes sense to include healthcare professionals', parents', and minors' perspectives in the design process of technologies for managing illness in everyday life. However, there is a lack of knowledge of how to balance these perspectives in design and capture the interrelation between the minor and the caregiver in managing the condition. The whole concept of mHealth and self-management has emerged with adult patients and is now increasingly being applied to minors. A very recent study attends to this as 'repurposed technologies for youth', pointing out that the area of self-tracking tries to fit adolescents into models built on adult users, and sees them as 'mini-adults' (Freeman and Neff, 2021). Although it is not spelled out in the literature, 'adultism' seems to characterise the area of self-management and design of mHealth technologies with minors that live with chronic illness. I use 'adultism' to account for how minors that live with chronic illness are viewed in light of adult perspectives.

Before I summarise my insights from the literature, a last point should be made about participatory approaches in design. Critical scholars in research areas outside digital health have argued that participatory approaches can be used to fulfil political and strategic purposes rather than direct interventions at peoples' needs, values, and experiences. Inviting people to participate in projects concerning an issue in their own lives can be used to secure funding, convince a group of people of agendas that actually have a top-down approach, and even turn the responsibility of solving challenges over to the participating group (‘victim blaming’) (White, 1996; Rogers, 2003). I did not meet such arguments directly in my readings of mHealth studies. However, the agenda of making minors capable of self-management is something to consider in this respect, not least given their marginal status and the political interest in making citizens capable of and responsible for managing their own health. Invitations to participate in mHealth projects and identification of people’s agency can potentially be seen as an excuse for laying upon this group the responsibility for solving their own challenges, while this might not be possible for children and caregivers, or could burden them even more.

In summary, just because children and parents are participating in design of mHealth there is no guarantee that this will produce technologies that accommodate circumstances pertinent to minors that live with a chronic illness. Although the design processes of mHealth do attend to centring design around minors and their perspectives we see that the technologies are still difficult to integrate with minors’ everyday lives and that outcomes are ambiguous. It is important to be attentive to the fact that digital innovation is also driven by other stakeholders and political, structural, and industrial purposes. Rather than relating to how minors live with their illness this *might* drive design towards approaching minors as becoming responsible and self-sufficient adult patients. The persistent mixed evidence in mHealth *might* point to the fact that adult approaches to self-management and participation are applied as defaults in mHealth design but hardly resonate with minors. It is these ‘mights’ that I endeavour to explore in this thesis. I wish to attend to minors as a particular group in relation to digital health innovation. The application of adult patient self-management models, adult design methodologies, and perspectives on minors as becoming adults must be exchanged for nuanced exploration of how minors practice and perceive illness and how self-management apps fit this picture.

Therefore, in this thesis I am not going to provide prescriptions for specific child-centred design approaches. The focus that I have tried to give in the paragraphs above is to the way mHealth innovation lacks consideration of minors as they are embedded in particular circumstances. This is despite researchers’ calls to look at agency and context, where mHealth design still tends to focus on the individual as receiver of the technology and executer of behaviour change. In this thesis I will immerse myself in the constructions of minors' realities, looking at their contexts of constraints and normative settings, and tracing their practices, social and structural positions, and perceptions. I will follow a research approach that allows me to explore what minors' living with chronic illness implies as it unfolds in their lived reality, rather than from an aspect of what it ought to become; and how mHealth design processes are geared to relate to this being of minors.

In the next chapter I will turn to how contemporary scholarly work has provided analytical concepts to account for people's lives with chronic illness and digital health technologies. This will help me develop a framework for studying the relation between minors' lived realities and mHealth development with an attention to how design is attuned to the particular circumstances of minors.

2. Analytical framework

In this chapter I will shape the thesis' analytical framework. I mainly draw on strands of the scholarly field of Science and Technology Studies (STS), a large interdisciplinary research field concerned with the interdependency between, and the practices of, science, knowledge, technology, and society (Jensen, Lauritsen and Olesen, 2007). I refer to scholarly works that are also used in the articles. Additionally, I refer to works, especially feminist STS, that help in constituting a coherent thesis on troubled attuning of mHealth to minors.

Overall, the analytical framework implies conceptualisations of the particular circumstances of minors in their lives with chronic illness and how these circumstances are reflected in mHealth innovation. Specifically, I focus on three particular circumstances of minors that seem crucial for mHealth innovation to consider when targeting technological designs towards them. These are conditions under which minors form *practices* around their illness, are *positioned* as target users in mHealth design processes, and *perceive* illness in relation to their lives.

In the following I first shape the conceptual concern with minors' *socio-material self-care practices* that enables me to capture minors' ways of engaging with people, things, norms, and challenges, as part of their establishment of illness-related practices in everyday life. Second, I shape the concept of *critical user-configurations* that enables me to capture design methodologies' (in)ability to align design with minors' specific structural and societal positions. Third, I form a conceptual attention to *ambivalence* in the way minors perceive life with chronic illness, in relation to mHealth monitoring of patient experiences.

These analytical concepts allow me to move away from attention to minors as either subjects of parental control or as autonomous and clearly delineated subjects of illness management. My analytical attention is instead focused on the contexts, materialities, structures, and situations that, along with the minors themselves, constitute their lived reality. This focus encourages a new emphasis on how mHealth innovation is attuning to minors and what issues should be considered around them.

Conceptualising *socio-material self-care practices* in life with chronic illness

mHealth innovation aims to improve patients' self-management and self-care practices. The ways in which patients establish practices around chronic illness and how they relate to medical technologies have been given great attention in STS. In this section, I primarily dive into such STS work and discuss conceptually how to explore the minor's practical relationship with their illness, body, health technologies, and with other context-specific actors involved in practices around their illness.

Socio-material and socio-technical assemblages

A crucial theoretical point within STS is how 'context' matters for the way a given health technology can be used to practice care and illness management. My use of the word 'context' up to this point however has been unnuanced and mistuned with the discourse of STS, as context annotates social constructivism – implying that social relations are decisive for how a technology works and how self-care and self-management are carried out. From now on I will from follow the terminology developed by social theorists of feminist epistemology (Haraway, 2018), STS (Asdal and Moser, 2012), and sociology of scientific knowledge (Law, 2004) that proficiently challenge the notion that behaviours and practices are exclusively socially constructed. These scholars began a turn to socio-materialism, arguing that materials (for instance technologies, spaces, and objects) are not passive objects subject to human will. Things, objects, and technologies participate as non-human actors, along with human actors in complex assemblages of interaction (Latour, 1993; McDougall *et al.*, 2018). Instead of thinking in terms of social contexts we should attend to how people, technologies, systems, and ideas interact and form changeable assemblages across multiple chains of interactions (Law and Hassard, 1999; Latour, 2005; Greenhalgh and Stones, 2010). A technology does not alone determine how it will be used and a patient does not alone determine how the technology can be used. A technology brings with it a certain 'script' for how it is likely to be used, by who and how (Akrich, 1992), yet, how the technology is employed depends on the situation and how the technology, the patient and the socio-material setting interact in making it work. Pols and Willems (2011) for instance, show how a telecare technology for people living with severe chronic obstructive pulmonary disease (COPD) performed very differently from what was expected when it was employed, while at the same time changing the patients' existing practices. Though the intention of the technology was to help patients to practice 'adequate illness behaviour' over a shorter period, some patients adopted them as more permanent 'life-lines' to the clinic. In other situations, these scholars show, the technology was incompatible with the existing apparatuses of the patients' homes (ibid). The ways in which technologies come to work in patients' lives are unpredictable and depend on existing routines, material arrangements, and the values of patients and relatives (Mol, Moser and Pols, 2010; Danholt and Langstrup, 2012), and specific situations. This is also why scholars have argued that the 'self' in self-care is misleading – practices of care are highly dependent on and entangled with an infrastructure that makes caring possible (Danholt and Langstrup, 2012). Rather, it should be called something like 'assemblage-care practices'. Alertness to the active participation of material and technical actors in the shaping of practices and orchestration of phenomena, such as care and illness management, have greatly influenced studies of health, illness, patients, relatives, medical devices, clinics, and databases (Berg and Mol, 1998; de Laet and Mol, 2000; Law and Singleton, 2005; Mol, 2007, 2008, 2010b, 2010a; Law and Mol, 2011). It is also this concept, of socio-material assemblages, that lays the foundation for my exploration of minors' self-care and self-management practices, i.e. an attention to the specific situational socio-material actors that form relations in caring for and managing illness, treatment, comfort, and well-being in minors' lives with chronic illness.

Patient work and tinkering

Another crucial point of attention in STS is the work it implies for patients, to adapt condition management technologies into their daily lives, in accordance with the socio-material setting (Corbin and Strauss, 1985; Mattingly, Grøn and Meinert, 2011). Various kinds of health technologies, for instance glucose-monitoring devices or apps for tracking symptoms, require patients to obtain new knowledge and skills (Mol, 2008; Mol and Law, 2017) and to reorganise daily living routines and interiors of their homes. Such a process of domestication of technology has been referred to as 'tinkering'. Tinkering accounts for patients' unconventional practices of handling, negotiating, and experimenting with integrating prescribed procedures and treatment devices into socio-material assemblages of everyday life (Langstrup, 2013; van Hout, Pols and Willems, 2015; Mol and Law, 2017; McDougall *et al.*, 2018). This tinkering is thus not to be understood merely as a way of integrating the technology and prescribed management practice into ones' life by 'following doctor's orders' and submitting to intended ways of using the technology. Rather, as Pols (2013) argues, the goal of patients is rather to find solutions, in order to live with the illness. Patients therefore find ‘borderland practices’ between the healthcare technologies and everyday life, where they can construct their own solutions to daily challenges with the illness and their management of it (Mattingly et al., 2011). Finding ways to integrate technologies and self-management practices into the lived reality of the patient thus implies altering the technologies’ intended usage and negotiating their value against other priorities in the patient’s life. By mutually adjusting the socio-material assemblages of everyday life and the use of technology, the patient, the setting, and the technology can form a relationship – they must attune to one another. ‘Socio-material’ thus alerts us to the thinking that human doings in the world and the way practices are formed are always a tinkering collaboration between people and things, a negotiation of purposes, and this implies an effort of work.

Attention to hidden care infrastructures

Feminist STS scholars like de la Bellacasa (2011) have put ‘care’ on the agenda of STS of health technologies and patients’ lives. Care work is crucial for getting us through the day – it is the productive activities that support our lives. Calls for care are everywhere, de la Bellacasa argues, such as in the rise of patient self-care technologies, but care is more complex than it seems to be. It consists of material and affective tasks that are complex and therefore difficult to account for, schedule, or enclose in fixed tasks that ‘start here and end there’ (López Gil, 2007). Care is everything we do to maintain and repair our world to allow us to live as well as possible, in the relations between our bodies, selves, and environments (Tronto, 1995). de la Bellacasa argues that if we want to explore and understand care, we must concern ourselves with neglected things. Care is subject to invisibility. Care studies imply asking who does the care work, how is it done, and for whom, and draws attention to those that are at risk whose voices are less valued (ibid). As de la Bellacasa (2011, p. 94) phrases it ‘[…] paying attention to care as a necessary doing […] directs attention to devalued doings that are accomplished in every context by the most marginalised – not necessarily women.’. It has been argued in STS that ethnographic studies of how technologies, practices, and illness mutually unfold in the lives of patients help make visible hidden ‘care infrastructures’. Care infrastructures account for the socio-material arrangements that enable and restrain the establishment of care practices that extend a single site and activity (Danholt and Langstrup, 2012; Langstrup, 2013; Weiner and Will, 2018).

However, little attention has been given in STS to minors as a particular group, and how the particular care infrastructures in which this group is embedded enables and restrains their engagement in establishing care practices and managing illness in everyday life. Furthermore, as I outlined earlier, attention to minors living with chronic illness has revolved around either parents as actors of care, or around adolescents becoming individual actors in their own care and management. On these grounds I argue that we need a particular attention to how minors engage as agents in practices of care and management, and to what their socio-material infrastructures imply.

Turning to minors' socio-material self-care practices

From an STS point of view children must, as any other kind of actor, be seen in relation to other human and non-human actors involved in illness care and management. Given the arguments of socio-materialism in STS we should turn to minors' care and management practices as socio-materially and socio-technically constructed, rather than seeing them in human-centric perspectives. Though the transition literature outlined earlier has accounted for minors' needs for, challenges in, and oppositions to managing their illness, it has been less attentive to how this group engages in complex practices of care and what their doings are an act of caring for. Minors have somehow remained an invisible actor, along with the hidden infrastructures that make care and illness management possible in their everyday lives. With the recognition that all (self-) care and (self-) management is accomplished by an assemblage of human, material, and technological actors, I find it helpful to use 'socio-material self-care practices' as an analytical framework for exploring minors' engagement in management of their illness and care of themselves. Socio-material self-care practices account for a combination of the scholarly concepts outlined above; how care is practiced is always a collaboration between human and non-human actors, given specific structures and values, and it demands work. Socio-material self-care practices urge me to recognise how minors in specific situations, along with things, spaces, time schedules, technologies, their bodies, and people around them, engage in establishing ways of taking care of themselves and managing their illness and well-being. This concept allows me to attend to minors' specific social, material, bodily and developmental realities, and their roles in practicing self-management, obtaining knowledge, learning skills, and caring. This prevents deterministic views of how medical devices, treatment, caregivers, and healthcare professionals are alone decisive in how illness is handled. It helps with avoiding perspectives on self-care and management as the doings of isolated individuals. It makes room for acknowledging an interplay between these actors and the minors, and furthermore the everyday life settings of minors, such as toys, digital and social relationships, and normative spaces, etc. In Article One, I will show how exactly these things interact with minors in negotiating and establishing practices of care for both their well-being and health.

To summarise, STS scholars have conceptualised patients' management and care for their illness as being socio-materially constructed. Integrating new healthcare technologies, like mHealth, implies a mutual attuning between the technology and the present practices. I employ a conceptual lens for exploring how minors engage in establishing self-care practices, given their particular relation to caregivers, the healthcare system, their bodies, peers, school, home, and everyday objects and technologies. I am furthermore attentive to learning and the takeover of responsibilities and tasks from caregivers, and to specific norms in relation to minors' socio-material realities. In my adaptation of concepts like practices, care, management, skills, and knowledge, I engage with processes of the minors' socio-material reality as continuous development – that is non-fixed, non-deterministic, and non-individualistic. This is a conceptual lens that enables me to see the particular ways in which minors relate to and negotiate technologies, and management tasks, and how their illness unfolds accordingly with the situations they are in and the norms and values that are specific to these situations.

Attending to the *critical* in user-configurations

mHealth innovation applies user-driven design methodologies. I now turn to conceptualising the ways in which mHealth design processes attune an emerging technological design to a particular target user group, in this case minors. I first provide an outline of conceptualisations of technological design and users in STS and feminist STS. I hereafter build a concept, *critical user-configuration,* that draws attention to the moments in the design process where significant shifts in user-configurations take place, shaping who *can* become a user of the design. I thereby direct attention to moments in design that are *critical*, in the sense of risky, for some user groups' 'survival' or 'exclusion' in the design process. My concept allows me to analyse technologies in the making, and in the making of user-profiles. It allows me to stay alert to how evolving user-representations throughout the design process moves away from representing only the initially decided target group.

User-configuration

Within the field of STS various scholars have contributed to conceptualisations of how health technologies make relationships with people, their illnesses, and the socio-material assemblages that form everyday life realities. Pols (2017) argues that we can only learn what specific technologies are and how they work by studying them empirically and analysing their relations to people in specific contexts. While I agree with this, my aim here is different from studying relation formations between technologies, patients, and assemblages in specific situations *of use*. Many mHealth technologies have failed to become of use to minors and such non-practices and non-relationships can hardly be explored in depth ethnographically. I instead seek to understand how relations between mHealth technologies and minors are prepared *in the making* – how they are scripted (Akrich, 1992) or readied in the phase of innovation/development/design. Therefore, I seek to conceptualise moments in making the technologies that become critical for whether the design is attuned to a certain target group.

In the past three decades the field of STS has continuously nuanced conceptualisations of technological design processes. Within this field scholars are interested in the interrelatedness between technological design and 'the user' – the person that is imagined using the technology, for what and how. Starting with the works of Akrich (1992) and Woolgar (1990) 'the user' has been conceptualised as a flexible imaginary abstraction of a certain kind of person that would be able to use the designed technology. According to this perspective the user is constructed, or rather 'configured', along with the entire technological development process that is driven by engineers and designers. Developers of a new technology define the preferences, motives, perceptions, and competencies of those that can potentially use the technology (ibid) and inscribe these characteristics into the design of the product (Akrich, 1992). These inscribed representations of a user and use-cases in the designed artifact mean that the technology comes to contain a 'script' – an embedded attribution and delegation of what specific competencies, actions, and responsibilities the user and the technological artifact must each entail. If an actual end-user is not matching the user-representation inscribed into the artifact it is likely that the technology will fail, as the technology depends on the appropriate collaboration of the user (ibid). The contemporary concept of *affordances* is used in STS to account for the functionalities and constraints that a technology or object provides to a structurally situated subject (Davis and Chouinard, 2016). This concept allows for critical engagement with questions of for whom a technology might provide opportunities or dissuasions and under what circumstances (ibid). Affordances regards the way technologies make some actions available to people, while entailing politics and values by these functions (Davis, 2020). Furthermore, scholars like Storni (2012) elaborated the process of user-configuration arguing that it is not only the developers that configure the user along with designing the technology. Rather, the purposes of design, the designers, participating stakeholders, technologies, methods, things, and 'the user' are mutually shaped in the technological design process. Other STS scholars have argued that while technological design shapes user-representations, real end-users also shape the technologies (Oudshoorn and Pinch, 2003) for instance by tinkering with the technology and integrating it into everyday socio-material assemblages, as outlined earlier.

Analytical interest in user involvement

Since the scholarly recognition that technological design affords certain kinds of users, and users in turn shape technologies, more STS studies of technological design have explored the interrelations between technologies and users, both in cases of technology in use and technology in the making. This increase in analytical interest seems to run conjointly with a shift from a technology-oriented to a user-oriented design paradigm in design theory since the late 1980s (Norman and Draper, 1986; Friedman and Cornford, 1991). Technological innovation increasingly seems to recognise the importance of ensuring that those people that the design is intended for are able and willing to use the final technologies. This has encouraged user-centred design and participatory approaches to technological innovation in the realm of health innovation, as I have outlined earlier. In STS studies of technological development and the user, scholars have also increasingly started following the involvements of users in design processes. For instance, Wong et al. (2015) are concerned with 'meaningful engagement' of patients in health informatics research, arguing that designing health information systems with patient-centred approaches might have its pitfalls. Wong et al.'s work points out that engagement of patients in design might produce design insights that make sense in the setting of design but not in the setting of the lived reality. For instance, patients might express a desire for a particular set of IT tools, but proceed not to actually adopt or use them, although they still perceive them as valuable (ibid). Another concept, *alignment,* is used to describe the process of adapting technological design to the subjects that are to use it. Andersen et al. (2014) uses *alignment of concerns* to bring attention to existing relations and practices with clinicians and patients that might serve as a point of rational departure for common concerns between these parts that an eHealth design could support. Here, alignment of the concerns of patients and clinicians are seen as prerequisites for the successful design of patient-centred eHealth services (ibid).

With scholars' attention to patients' involvement in the design of health technologies thus comes an analytical attention to the relation between users' participation in the design process, their agency in shaping the design, and their use of the final design. Stated in basic terms, I see three types of users in the design process that STS can attend to; the specific person participating in the design process that represents the intended target user of the design, the abstract user that designers and other actors in the design process configure, and the end user that is the actual person that integrates, tinkers with, or rejects, the final technological design. In the STS studies of user-configurations these three categories of users are probably intertwined and overlapping. However, in my study I find it relevant to distinguish between these categories. My study of mHealth design processes concerns the shift between the first two categories of users. I look at how minors are initially involved as representatives of the target user at whom the mHealth projects aim to direct the design.

I aim for a concept that can account for the process of attuning a technological design to a particular group of situated subjects. This is a concept that implies a technology development's way of tuning in to the structural, political, and juristic boundaries of a certain group, and taking into account such positions of a target user group. By *positions* I mean the way the targeted group are restrained and enabled to take part in managing their illnesses, given their specific embedment in socio-material, cultural, political, and juristic structures. Minors are positioned differently to adults, for instance in terms of their boundness to parental custody, dependency on support, and limited autonomy. I wish to explore how the script of mHealth is informed to fit minors' positions in relation to their own health. I seek to conceptualise moments when the configured user-profile stops fitting minors' specific structural and socio-technical positions in management of their illness. To shape a conceptualisation that is sensitive towards issues of accounting for minors' particular societal positions I devote the next paragraph to a short outline of feminist STS. Feminist STS has contributed to conceptualisations of technological innovation and the user, with a strong sensitivity to bias, marginalisation, and discrimination in technological and scientific development. These scholars' critical attention to the inabilities of innovation to encompass some groups will help me in shaping a concept of *critical user-configurations* to support me in attending to minors' particular positions in technological design processes.

The sensitivity to structural bias

Feminist STS emerged out of second wave feminism in the early 1960's with an ambition to, or maybe rather an urge to, work against suppressive effects and social inequalities in knowledge production and technological development (Adrian, Skewes and Schwennesen, 2018). Scientific feminist scholars started questioning the values and interests of scientific and technological endeavours. What groups are favoured and what groups are neglected in technological and scientific production? Who gets to decide what scientific and technological undertakings are important? Stated in brief, such questioning led feminist scholars to reveal how groups, especially women, are marginalised in research on gender and sex, on health issues, and in technological innovation. Following such findings, and after criticism from feminists of colour and post-colonial feminists, the feminist scholarly movement expanded its area of concern to also include studies of how categories of class, race, ethnicity, and age intersect with science and technological development (Crenshaw, 1991). We thus have a scholarly movement that makes space for questioning values, norms, and structures in scientific and technological innovations, and that through specific studies exposes groups that are neglected, overlooked, marginalised, and discriminated against.

In their endeavours to expose mechanisms of marginalisation feminist scholars explored the technological design process as a decisive site in which groups of people can use a final technological design (Lerman, Mohun and Oldenziel, 1997; Cynthia Cockburn, 2009; Sun, Nasraoui and Shafto, 2020). For instance, Oudshoorn et al. (2004) were interested in knowing why new electronic products and services were often used more by men than women. This resulted in accounts of barriers in design to adjusting for a diversity of users and needs. The scholars showed how designers' own identities, for instance as males, came to prioritise certain kinds of, here male, users of the design and thereby constrained the development of technologies for a diversity of users. Furthermore, feminist scholars have emphasised that we should attend not only to those who use a technology but also to those who do not, seeking out reasons for non-use among certain groups

(Oudshoorn and Pinch, 2003; Wyatt, 2003), so as to explore differences in preferences but also possible bias towards some groups (Oudshoorn, Rommes and Stienstra, 2004). Feminist scholars have raised awareness of how structural, historical, and cultural bias affect user-configuration during design (Lerman, Mohun and Oldenziel, 1997; Cynthia Cockburn, 2009). At an overall level the feminist objectives aspired to new ways of studying science and technology production from a critical perspective (Adrian, Skewes and Schwennesen, 2018). For instance, Martin (2017) showed how stereotypical perceptions of men and woman influence how medical scientists perceive their research on the egg and the sperm. Through such critical work feminist STS exposes how science and technology are always culturally and politically entangled. Knowledge production and technology are never objective or independent of the norms, values, or interests of the situations in which they emerge (Wyer, 2014). One of the leading figures of feminist STS, Haraway (2016), argued that because technologies are situated in context and practice, they are to be analysed as such. Only partial truths can be produced of the situations of knowledge and technology production (Haraway, 1988). Feminist STS has thus, through a critical and non-neutral approach, enabled making explicit how political agendas are embedded in the way research and technological innovation are carried out.

This means that feminist STS has pointed to the site of technological innovation as an area for exploring how technologies come to favour some groups of users over others. We must be attentive to how designers, but also cultural, structural, and historical categorisations and perceptions of different groups, inform design and the imaginaries of who the user can be. Though feminist STS has, to my knowledge, been less attentive to minors as a marginalised group the critical perspective can help me attend to how minors are reflected in technological innovation. Following this short outline of feminist attention to users and technological innovation I will now sharpen my conceptual attention to design processes and minors as users.

Critical user-configuration

Whereas feminist scholars attend to how the design process for an everybody-user comes to favour some groups over others, my interest is directed towards a slightly different phenomenon of technological innovation and users. The phenomenon I consider is mHealth design projects that *initially aim* to target the design at a very specific group of target users – minors that live with a particular chronic illness – and their *challenges* in accounting for this groups' specific positions as situated subjects throughout the configuration process. As I will show in Article Two, the design methodologies are not geared towards taking into account the specific socio-material, structural, and positional circumstances of minors, nor can they combine this with other priorities in the projects.

There is a scarcity of conceptualisation that helps pinpoint the moments where design and the configured user-profile turns against the initially targeted user group and explores these moments in depth. With a feminist preoccupation with how technological development can be biased against specific groups I wish to expand the scope of the conceptual term *user-configuration*. I add a two-sided notion of *critical* to the concept of user-configurations. The two-sided notion of criticality is stimulated by Kaufmann et al. (2020) that in one sense turns to *critical moments* where it is decided what data can exist. In another sense *criticality* accounts for an occupation with what political character the data carry. Inspired by this I explore the configuration of users in a two-fold critical perspective. In the first meaning I look for critical moments where it is decided which groups can become users in a technological design process. This means that I account for when minors' fit of the emerging user-profile is in danger – when the attuning between the design and the minor is at 'a critical stage'. In the second meaning I take a critical stance towards the politics that are embedded in the structures around technological design, that become decisive for the selection of some groups over others as end-users of a technological design. I here explore how larger structural settings play a part in the design process, shaping what groups the user can represent. With the concept *critical user-configuration,* I thus attend to moments where the design process becomes decisive for who becomes the user. Attending to these moments allows me to explore how various actors and structures are drawn in to inform the design's functionality and purpose, but in doing so come to bias the design towards specific groups and against others. The concept of critical user-configuration thereby implies my 'sticking to' the target group, and my continuously questioning whether the design resonates with the specific socio-material assemblages and positions of minors – my critical stance.

In a final summarising note, with critical user-configuration I make possible an ongoing attention to how an emerging user-profile at different points of a design process represents the group they are targeting. Furthermore, this concept allows me to study how design methodologies are geared towards taking into account and attuning the design with the technological and societal positions of this group.

Ambivalence in life with chronic illness

mHealth enables monitoring of patients' illness experiences. I now turn to a conceptual framework for understanding how minors perceive the relation between illness and their everyday lives, in relation to monitoring their illness experiences. I first introduce contemporary STS work and post-phenomenological work on how monitoring technologies affect the ways patients perceive illness in their lives. Drawing on STS scholars that give attention to how people can have ambivalent attitudes towards monitoring technologies, I argue that we need to also be attentive to ambivalence in the ways minors perceive their illness in relation to mHealth. I shape the concept of *ambivalent living* to enable a nuanced understanding of how minors form their perceptions of life with illness, accordingly with everyday situations. Such a concept is open to minors' flexibility in how they perceive their illness, rather than proposing a fixed link between illness and everyday life.

STS on monitoring of patients' experiences of illness and health

As outlined earlier, mHealth technologies enable patients' own monitoring of illness in the realm of their everyday lives. This is hoped to make possible the targeting of healthcare services to patients' exact needs, and furthermore support patients in improving their self-care and illness management. Prainsack (2011, 2014) refers to the 'participatory turn' in healthcare, where technologies like mHealth have been given the role of facilitating patients' perspectives and involvement in their own care practices. While patients are no longer seen as passive subjects of healthcare providers' orders and suggestions (Kingod, 2020) they are identified in terms of their agency as 'the active patient' (Barbot, 2006; Rabeharisoa, Moreira and Akrich, 2014), 'the informed patient' (Kivits, 2004), 'the expert patient' (Fox, Ward and O'Rourke, 2005) and 'the expert of experience' (Nielsen and Grøn, 2012).

STS scholars have furthermore drawn attention to technologies that make possible 'self-tracking' of one's own health. For instance, Ruckenstein and Pantzar (2015) use 'personal analytics' to refer to measuring various mental and bodily functions, including physical activities, everyday movements, and body weight, with the aid of technological devices such as pedometers, sleep trackers, and heart rate variability measuring devices. This research interest resonates with studies of 'the quantified self' which covers the phenomenon of some people's daily use of self-monitoring tools that offer insight into their own lives as a set of numeric data that the individual can examine and act upon (Lupton, 2015). Within this scholarly field it has been argued that the quantified self is a reference to an ideal type of person – one who is enthusiastically engaged with improving themself – thus encompassing an assumption that when people 'know more' they will modify their behaviour accordingly with this knowledge (Lupton, 2014).

Patients' own monitoring of their health and illness is argued to reflect political neoliberal orientations of self-sufficiency, citizen autonomy, and individualism. Critical voices question whether the participatory turn of healthcare is thus creating a scapegoat for legitimising a neoliberal responsibilisation of citizens (Lupton, 2013). While managing disease was previously regarded as the responsibility of healthcare professionals, contemporary views underline the importance of a partnership between patients, relatives, and healthcare providers (Wagner *et al.*, 2001; Barr *et al.*, 2003; Coleman *et al.*, 2009). Here self-monitoring is regarded as an essential strategy for patients' self-management (Bartholomew et al., 1993; Norris, Engelgau and Narayan, 2001; Bodenheimer et al., 2002; Farmer et al., 2007), implying patients' tracking and processing of their own health information (Jiang and Cameron, 2020). Furthermore, the anthropologist, Wahlberg (2015; 2020), argues that healthcare services increase the focus on 'chronic living' or 'morbid living', which implies an attention to the connectedness between life and illness. He attends especially to the increase in initiatives aiming to improve people's quality of life, health, lifestyle, and well-being (Wahlberg, 2017).

How monitoring technologies affect perceptions of illness and living

Technologies shape socio-technical, cultural, and normative aspects of illness (Hofmann and Svenaeus, 2018). Technologies can for instance affect the 'prestige' of specific diseases (Album and Westin, 2008; Album, Johannessen and Rasmussen, 2017). The use of advanced technologies can ascribe to the disease a higher level of importance, in contrast to an illness that is merely experienced by the patient. As opposed to illness experiences that are by nature invisible and individually perceived (Conrad and Barker, 2010) technologies can move individually felt illness into the realm of control and responsibility in a social and normative context, if it can find ways of measuring it and making it visible (Hofmann and Svenaeus, 2018). Technologies can thus help in making illness visual and communicative in cases where patients merely rely on their own experiences to relate to and explain their illness to others.

As Mol (2000) importantly argues, technologies designed to generate knowledge always bring with them certain ways of perceiving a person's health. Similarly, the anthropologist Oxlund (2012, p. 53) argues that a 'numeric ontology' provided by health monitoring technologies pervades the 'ways in which people relate to their own bodies'. Schüll (2016) argues that data-monitoring not only concerns the bio-medical aspects of life but also issues like daily choices, rhythms, and preferences. Lehoux (2008) further argues that there is a recursive relationship between illness and the monitoring of it, where monitoring makes prominent the (unpredictable) illness in ways that do not necessarily reduce the patient's anxiety and attention to it. Technologies affect the way patients perceive their health conditions – they shape illness experiences (Hofmann and Svenaeus, 2018), besides monitoring them. For instance, blood sugar measurements enabled by monitoring devices can affect the ways in which patients living with diabetes perceive their symptoms (ibid). By comparing numbers and visualisations of the body's state with their bodily sensations the patient can learn to be more alert to such sensations. Treatment technologies might affect illness experiences in the sense that they relieve or eliminate symptoms (Hofmann and Svenaeus, 2018). Likewise, I imagine that monitoring technologies can show that the patient is in a good state of health, and thereby relieve the patient from worrying about illness.

In other cases, technologies can through biomedical measures reveal disease that the person did not know about. Health technologies can create illness awareness in situations where patients thought their illness insignificant, by encouraging them to refocus attention to it (Hofmann and Svenaeus, 2018). Hofmann and Svenaeus articulate this in terms of how technologies 'shape' patients' experiences by providing the patient with certain foci and patterns for understanding their illness. In this sense health monitoring technologies can make aspects of 'ordinary life subject to measurement, attention, and medical interpretation' (ibid, p. 6). Illness can be created in the patient's life where it did not (in the person's perspective) appear before '(ibid). By questionnaires, tests, and attention to experiences of mood and other emotional states, technologies might furthermore transform these experiences into something that the person relates to illness (ibid). Technologies can thus make people redefine certain ordinary life experiences as illness-related where these were otherwise seen as 'normal' – that is, in this perspective, illness-free. This means that, in addition to transforming the way the ill body is treated, technologies also transform the way people experience their illness (ibid), and possibly the link between illness and everyday living. In this sense health monitoring technologies can support patients' insights into their own experiences of illness in everyday life, yet also affect how the patient and their social relations *perceive* the illness in everyday life. In such thinking, technologies help to shape how people perceive and understand the world (Veerbek, 2005) and thus also how they perceive their life with chronic illness.

Ambivalence as an approach to how minors perceive illness in their lives

The aspects described above provide insight into how technologies can change people's perceptions of the relationship between illness and otherwise 'normal life' experiences such as mood, emotions, and activities. My interest here is in how monitoring of, and thereby increased attention to, how illness affects everyday living might cause patients to give greater consideration to their illness' impact on their lives. I seek a conceptualisation of how minors' perceptions of illness in everyday life are shaped and what monitoring of their own experiences of symptoms, treatment, functional status, and quality of life with mHealth implies, in a perceptual sense. Recently, STS scholars have turned to 'ambivalence' to nuance understanding both of how people move between engaging and disengaging with health monitoring technologies, and of how positive and negative consequences of using these technologies can shift across environments (Lupton, 2017; Ruckenstein and Schüll, 2017; Marent, Henwood and Darking, 2018). Patients can sometimes find it meaningful to track their health and sometimes find it disappointing or frustrating. To avoid studying either 'resistance to' or 'acceptance of' digital health technologies Marent et al. (2018) nuances how patients display ambivalence in both accepting some dimensions of the technology (e.g. wanting to see their treatment history) while rejecting other dimensions (e.g. not wanting to be reminded of the condition regularly). The technologies both have affordances that individual patients reject, and some that they accept or want, according to the situations they find themselves in.

In employing this thinking to minors and mHealth, I am interested in understanding how minors perceive illness in relation to their daily lives, and whether and how monitoring of patient experiences with mHealth gives rise to ambivalence. Because many studies have underlined minors' preoccupation with normality while living with chronic illness (Lambert and Keogh, 2015), I am interested in how mHealth apps that attend to their experiences of a wide variety of aspects of their lives (for instance symptoms and mood) affects minors' perceptions of the role that illness plays in various situations. I use *ambivalent living* to be alert to the recognitions that illness and daily living might not merely be connected, but connected in certain ways according to situations, social encounters, physical activities, and normative spaces. In this sense ambivalent living contrasts notions of 'living with' or 'chronic living', that is a whole-life or whole-person paradigm, because such a perspective implies perceiving chronic illness as constant, continuous, and connected to the entirety of patients' lives.

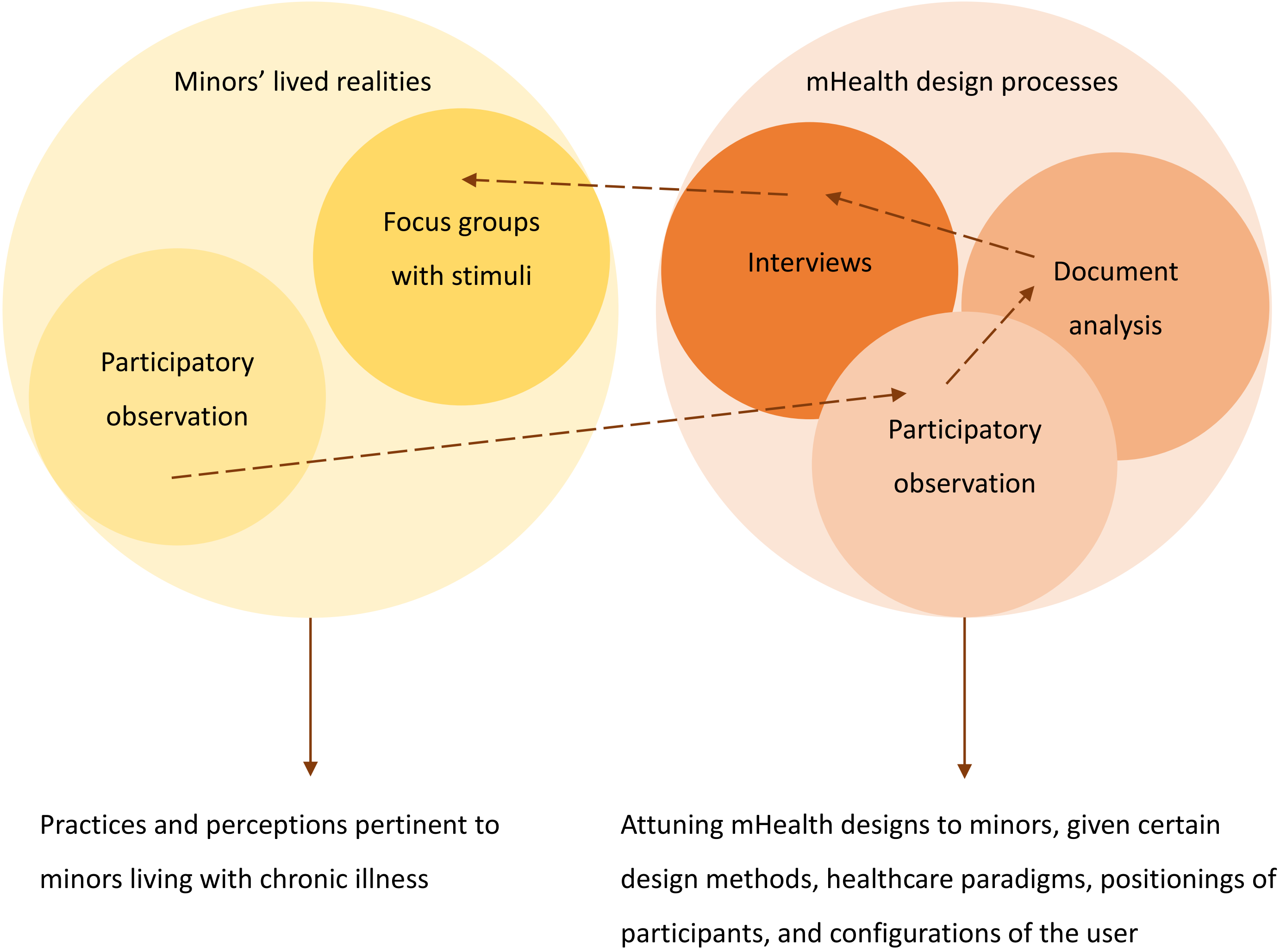
To summarise, scholarly works highlight how patient monitoring can make patients redefine aspects of their lives that they otherwise find ordinary and illness-free as being related to illness. There is thus a recursive relationship between monitoring patient experiences and changing these experiences *because* one monitors them. Studies of minors living with a chronic illness have especially highlighted how a sense of normality is valued but is hampered by extensive demands for attending to and managing their illness. Given that mHealth can imply measures of many different experiences of 'life with illness' I am interested in knowing how monitoring of various experiences make sense to minors and their perceptions of the interrelationship between their illness, their life, and their striving for normality. Through the concept of ambivalent living, I can enable a focus on minors' perceptions of illness that provides a more nuanced perspective on the situations and aspects where monitoring of some measures make sense while other aspects might be rejected.

In summary, in this analytical framework chapter I have attended to three specific circumstances of minors that seem to make them a distinct group in relation to mHealth innovation, in comparison to adults. Minors' establishment of illness management *practices* in relation to mHealth-enabled self-management, their *positions* in relation to user-driven innovation processes, and their *perceptions* of life with illness, as in relation to monitoring illness-related patient experiences, seem to demand specific attention. I have outlined three sub-concepts that help me explore these three aspects, with specific attention to the socio-material, structural, and situational settings with which minors are entangled. Turning analytical attention to practices, positions, and perceptions that make minors a distinctive group helps me explore the attuning of mHealth to minors in a way that exceeds patient-centredness. As I not only focus on what minors do and say concerning their illness, but also on socio-material and socio-technical dimensions of their everyday life, the mHealth design setting and minors' ambiguous realities, I enable exploration of complex assemblages of minors' particular circumstances in relation to both mHealth innovations' reasonings and design methodologies.

3. Methodology: undertaking a double-sited ethnographic study

I now turn to the methodology of the study. I will provide an overview of data and reflect upon the process of analysis in a later chapter. The study was based on ethnographic fieldwork in minors' homes, in two mHealth projects, and on focus group discussions with minors, parents, and a hospital youth panel. Figure 2 (below) illustrates the methodological composition that was based on multiple qualitative methods, across what I call an 'ethnographic double-site'; minors' lived realities and mHealth design processes.

Figure 2 Overview of ethnographic sites and main methods used in the study. The arrows indicate the order in which I made use of the various methods; first in the site of minors' lives, then in the mHealth projects, and finally in a return to minors' lives. Below the sites are indicated the kinds of knowledge I gained in each site.



By my ethnographic fieldwork in both sites, I have gained insight into how mHealth projects are attuning to the particular circumstances that I see in the site of minors' lived realities with illness. In the following I outline how my establishment of a double-sited methodology takes inspiration from techno-anthropology and situational analysis. Then I describe and reflect upon methods and emerging ethical considerations in studying minors' practices, design processes, and their perceptions of life with chronic illness. At the same time, I reflect upon my positioning. Lastly, I reflect upon 'participation' in qualitative research.

A double-sited ethnographic exploration

Here I outline my double-sited ethnographic methodology, which is partly inspired by techno-anthropology's attention to design processes and the user, Haraway's (2016b) notion of 'troubles', and Clarke's (2005) 'situational analysis'. I argue that looking at both the site where technologies are designed, and the site where its final product is meant to work, provides important knowledge about each of these sites' complexities and about contradictions between them.

Techno-anthropology

I have an educational background in techno-anthropology, which is a newly established scholarly field. As the name indicates, research within this field characteristically implies using anthropological methods to learn about the different logics that influence human capabilities, mediated by techniques and technologies (Børsen and Botin, 2013) – that is, human-technology interactions. Techno-anthropology particularly finds its application in studying and supporting product development. A techno-anthropologist is considered to enable new ways of reflecting critically on the shaping of patients' needs and values (Wong *et al.*, 2015) and on the participatory setting of design (Nøhr and Kanstrup, 2013). The researcher must obtain a 'hybrid sensitivity' towards the interactions in the design process, between users, experts, design artifacts, and technologies (Botin, 2013). A techno-anthropological study demands an active participatory engagement of the researcher in the processes (Wong *et al.*, 2015). As Ruckenstein and Pantzar (2015) argue, the techno-anthropologist endeavours to examine technology in relation to contemporary worldviews and practices.

The study of this thesis is techno-anthropological in the sense that I, as a researcher, participated in the mHealth design processes and the settings of the target users. Furthermore, I have been sensible to the ethical and sustainability-oriented dimensions of the interactions between social, material, and political actors in the design of new health technologies. I share these sensitivities throughout the chapter. Similarly with the points made by Wong et al., and Ruckenstein and Pantzar, I have attended to perceptions of patients and a contemporary paradigm of healthcare innovation. I have explored how the design relates to a target groups' practical and perceptual settings where the technology is to be used. I try to answer why mHealth innovation is challenged in attuning the technologies to minors, and what purposes, stakeholders, actors, norms, and innovation methodologies are at stake in this.

Troubles

Contrary to a more typical ambition to support the technological development, I aim in this study to advance knowledge about the challenges in the interrelations between digital innovation and minors' lived realities. I seek to 'stay with the troubles' (Haraway, 2016b) of attuning mHealth to minors. In introducing her greatly celebrated book 'Staying with the Trouble', Haraway presents her key term 'trouble' in the sense of 'disturbing', 'stirring up' and 'making cloudy'. Haraway draws on multiple feminist scholars in her exemplification of what staying with the trouble implies, as she aims to move STS away from both dystopian and utopian approaches and into situated accounts of various issues. We should study what disturbs, make frictions (Tsing, 2011), or troubles different kinds of lifeforms, and immerse ourselves in these relations. With her notion of troubles, Haraway urges us to keep from striving to fix problematic issues in light of our (technophile) ideas about the future. Instead, she proclaims, we should find ways to be truly present in unfinished configurations of places, times, matters, and meanings. Making trouble and staying with trouble is a way of accounting for relationships that are not stabilised, and at the same time offering other opportunities for companionship with human and non-human actors in the world. As Marent et al. (2018, p. 18) phrases it, 'responsible research and innovation in the field of digital health requires us to embrace ambivalence rather than seek to resolve contradictions and avoid conflicts'. To *trouble*, has in feminist STS come to mean questioning what is otherwise not questioned in science, society, and technology, and thereby to start debates. It is about becoming able to trouble norms and identify biases where they are otherwise unquestioned.

While the literature bears witness that there are challenges in developing mHealth for minors, little fuss has been made of this and the field pushes on to reach results. There is no fundamental disturbance over whether and how mHealth and minors *can* relate, rather a persistence in keeping on until it works. Therefore, the knowledge I seek is about the challenges that lie beyond the technological bugs that need to be fixed. Suggesting fixes could in fact draw attention away from the interesting relational realities that troubling otherwise helps to expose. I seek to point to the troublesome relations that minors, and their settings, constitute in our increasingly digitised healthcare system. Furthermore, I seek to point out the complex relations mHealth innovation has to specific technological practices, stakeholders, and certain patient populations. By staying with the troubles of attuning I seek to make visible and explore otherwise hidden assemblages that characterise minors and mHealth innovation.

A methodology inspired by situational analysis

The placement of my ethnographic investigation must encompass both the site of design and the site of where the design is intended to work. Marcus (1995) proposed 'multi-sited ethnography' as a method of study where participatory observation is carried out in multiple places to explore dichotomies, for instance between life worlds and systems. Such studies not only stay in one place but follow people, things, metaphors, conflicts etc. through their different manifestations. The research is planned around the connections, relations, threads, conjunctions, or juxtapositions between sites, where the ethnographer is the one that establishes an actual physical presence and a logic about the connections between these sites (ibid). Feminist STS scholars have, in extension of Marcus' framework, provided a methodological/analytical package approach to multi-sited ethnographic projects (Clarke, Friese and Washburn, 2017) called 'situational analysis'. Situational analysis is much inspired by Haraway's thinking (2003, 2014) and implies an attention to how things make sense in their particular situational settings. Situational analysis enables research of entanglements of the human and non-human and goes beyond 'the knowing subject' (Clarke, 2005, p. xxviii), thus, in my case, beyond the minor and the mHealth designer.

One kind of situation that I turn to is where illness is practiced in minors' lives. Another is where illness is perceived and experienced. These kinds of situations are probably overlapping, but not completely, as some things can be perceived without enactment. Furthermore, the situation I turn to in mHealth innovation is where the design is attuned or not attuned with minors' societal and structural positions. This means that I have commuted back and forth between the site of minors' lives and mHealth innovation. I have, in the site of minors' lives, ethnographically explored the socio-material constructions of illness practices and let this shape my focus on the user-configurations in the mHealth projects. I have furthermore ethnographically explored discourses of the user-driven design and 'patient-centred' approaches to patients in mHealth projects, and taken these perspectives as points of discussion with minors and parents in focus groups. Turning to these situations has helped me to make the usually invisible practices, positions, and perceptions of minors visible in relation to mHealth. It has helped me to expose key elements of the situations in which the phenomena are embedded. Lastly, it has contributed to exposing discursive positions taken by actors in the assemblage, as suggested by Clarke (2005).

The methodology of a situational analysis study implies a multiplicity of methods that can elucidate the complexities that lie beyond what individuals can voice. 'Situational analysis allows researchers to draw together studies of discourse and agency, action and structure, image, text, and context, history and the present moment – to analyse complex situations of inquiry broadly conceived.' (Clarke 2005, p. xxii). The objective is not to simplify but rather to capture complexities and make contradictions and ambivalences clear (ibid). Clarke (2003) disarticulates grounded theory from its positivist roots and has an ecological ambition to bring attention to the organisational, institutional, discursive, and practical sites of which the study concern is part. She supplements concern with basic social processes with openness towards finding alternatives centring on attention in the situations, and includes a postmodern analytical attention to the non-human. The non-human in the situations that researchers explore deserves explicit inclusion in research and analysis. Situational analysis is a way to study how the human and non-human are co-constitutive and 'make each other up', which is a perspective drawn from influential scholars situated in studies of science and technology (Latour, 1987; Haraway, 2004, 2013). The theorising aim in Clarke's objective is an ongoing process rather than an ultimate goal. Methodologically, situational analysis demands a flexible means of research design that can facilitate multisite research into both physical and textual materials, along with ethnographic material to account for and embrace complexities of the research issue. Clarke's emphasis on variation and differences is put at the centre of attention which she argues speak to the importance of accounting for issues' situatedness. I have taken from situational analysis an attention to how enactment of practices, positions, and perceptions can vary across situations in different sites. I have employed both ethnographic methods and analysis of discourses in materials and documents to explore what digitally enabled self-management implies in the site of minors, and in the site of mHealth innovation, respectively.

Below is a table of the various methods I used to enable analysis of both the situations of minors' perceptions and practices of illness and the situations of mHealth development. These situations' complexities demanded my hybrid sensitivity to different logics, and flexibility in methods to study discourses, practices, perceptions, and positions, which I will elaborate in the following paragraphs.

Table 1 Overview of methods used in the study

Method	**Means**	**Making sense of…**
Participatory observation (in minors' homes and in mHealth projects)	Observation Participation Conversation	Practices between human and material actors Interior and daily organisation Affective and normative environment Processes of learning
Photography by researcher (in minors' homes and in mHealth projects)	Shared attention to materialities and practices	Everyday life objects and practices Associations of illness, management, and socio-material collaborations
Document analysis (in mHealth projects)	Collection and reading of reports and other materials of the design processes	Positioning of design participants Design methods Evolvement of design and user-profiles Visions and logics permeating the design
Interviews (in mHealth projects)	Interviewing	Past and present experiences, opinions, visions, and ideas Structures and positions of participants
Focus groups with stimuli (with parents, minors and a youth panel)	Group interactions Discussion Difference of opinions	Perceptions Discourses and norms Experiences Imaginative futures

To summarise, my methodological approach is made up of a techno-anthropological orientation towards design processes and the user and a situational analysis approach to elucidate the complexities of, respectively, the design site and the target user groups' site. I term this a double-sited methodology. This allows me to focus on situations of minors' care and management practices and their perceptions of illness in their lives, and to see this in the setting of situations of designing with and for minors in mHealth projects. I bring knowledge from minors' realities into my study of design processes and configuration of the user. I then bring knowledge of the paradigms and logics that the design teams inscribe into mHealth designs into discussion with minors and parents.

Studying illness practices in minors’ everyday lives

To gain knowledge about minors’ practices of care and management of their illness I recruited minors that live with haemophilia and with JIA, with whom I could carry out participatory observation in their everyday lives. I first contacted paediatricians at two haemophilia paediatric centres and a hospital unit for children and young people living with JIA and explained my research aims. The paediatric healthcare professionals were interested in my research aims and invited me to join their daily consultations with patients and parents to recruit research participants. Over approximately 6 days of consultations I explained to 19 patients between the ages of 6 and 18 and their accompanying parents the study ambition of exploring mHealth’s relevance and applicability to minors living with chronic illness. Subsequently I asked if they would like to participate in my study. Of the 19 minors that I asked 17 of them, between the ages of 7 and 17, and their accompanying parents, agreed to participate. Two patients aged 16 and 17 declined to participate because they did not want to place more attention on their condition. Also, one of the participants’ parents decided to withdraw from the study after I had carried out participatory observation with them. These parents stated that they wanted to keep their experiences private and worried that they could be identified in my material, despite anonymisation. This could possibly compromise their already challenging relationship with healthcare professionals. Furthermore, one of the participants that was recruited in one of the haemophilia units did not suffer from haemophilia but from blood clots. The associated paediatrician explained that the patient had been referred to the paediatric haemophilia unit because she did not fit the adult healthcare services to which patients with blood clots were usually referred. I still decided to invite her as a research participant because her (mis-) placement in the haemophilia clinic spoke to my research aim of exploring healthcare services’ attuning to minors’ particular circumstances. She agreed to participate and the insights I gathered through participatory observation in her domestic life setting increased my attention to minors’ abilities to find ways to adjust themselves, their situation, and their socio-material settings accordingly with their own preferences, yet within organisational, structural, and technological boundaries. While this girl is not directly referred to in this thesis, my acquaintance with her permeates the thesis in its aim to report on marginalisation of minors. She had an extraordinary ability to make the best of her situation and convert her status as the ‘odd one out’ in a categorical healthcare system into a genuine interest in her own health and treatment. Her ability to work on adapting her socio-technical setting accordingly with her preferences and interests was something I also recognised among the rest of the minors that took part in the study, and to which I will return in Article One.

I carried out participatory observation of two to three hours duration in the homes of 6 minors living with haemophilia (all boys), 9 minors living with JIA (6 boys and 3 girls), and one suffering from blood clots, all between the ages of 7 and 17. 39 family members were also included in the participant observations, which took place in Denmark, in the period between December 2017 and May 2018. All the minors and their parent(s)/caregiver(s) received verbal information from me about the study’s aim of generating knowledge about how it is for minors to live with chronic illness, and how this relates to mHealth. Furthermore, I explained what their participation would imply, that this had nothing to do with their access to or use of healthcare services, that they would be anonymised, that I was not a healthcare professional but interested in the social and practical ways of living with illness, and that they could at any time ask questions or withdraw from the study. They provided informed consent and are represented by pseudonyms in the study. I had initially conceived of following minors around different spaces of their lives, however all but one declined having me following them outside their home setting, for instance in school or leisure activities. The reason for this was (again) that my presence would draw more attention to their illness. The minors and parents wished to limit how much attention was given to it. This served as a preliminary insight into the situations that characterised their illness and into their attempts to control when to attend to illness and when to background it, both of which I could explore more during participatory observation, and later through focus group discussions.

Ethnographic participant observation and photography

Participant observation is an ethnographic method for experiencing and understanding how the world looks and how reality is for those who are studied (Hastrup, Rubow and Tjørnhøj-Thomsen, 2011). It is about taking part in someone’s life (Madden, 2020). By being there, observing, having conversations, and taking part in activities, the researcher is allowed insight into and sensations of practices and interactions (Skovdal and Cornish, 2015a). This method is important for obtaining insight into what people *do,* because people are generally unable to account for their daily practices in interviews. With participant observation the researcher can observe behaviour, interaction, and unarticulated work between people and things in their natural setting (ibid). Though participant observation studies are often long and imply that the researcher is gradually involved more and more as part of the setting that is of interest, my study with the minors was merely a one-time experience where I was positioned as a visitor to their domestic lives. The families agreed that I could visit them once or twice given the previously mentioned value on limiting how much attention was given to the illness. Because my aim was to uncover the practices, interactions, and socio-materialities of illness my presence in their homes increased attention to their illness. The parents' agreement to let me visit became a balancing act between, on the one hand their wish to contribute to knowledge about life with chronic illness for minors and finding it interesting to be part of such a study, and on the other hand risking an increase of attention to the impact of illness in their lives by having a researcher attending to it.

My way of doing participant observation was first to sit and talk with the parents and minors together to tell them who I was and that I was there to get a sense of what it was like being a minor with chronic illness. In these conversations I asked less about the parents' views and more about the minors' daily lives and interests. This allowed the minors to recognise me as one that their parents could accept, while at the same time as one that was mainly interested in them, the minors, and less in adult perspectives on illness. Shortly after my introduction I asked each minor if they could show me their room or something that had caught their interest. We then left the conversation with the parents and in most cases spent an hour or more where the minor introduced me to their everyday life at home. I encouraged the minors to show me things and practices that were connected to their illness while showing me around. Whereas, when I asked them to participate in the study, they had often said that illness did not have a great effect on their daily lives, apart from 'when something happened' in terms of injury or fluctuations of symptoms (or in the case of a researcher's visit), we together discovered how illness and management had subtly been inscribed into many aspects of their lives. The minors and I were commonly surprised to find so many parts of their homes, domestic objects, daily routines and practices, sayings, and interactions, being somewhat connected to illness. For instance, most of the minors told me about playing with teddy bears and dolls, through a treatment narrative where they were the ones to treat these stuffed animals the way they themselves were treated. Such practices I describe in Article One. Furthermore, I asked the minors (and parents) for permission to take photos of items that had something to do with their illness, which resulted in around 100 images of various treatment-related or everyday objects and doings of the minors. The photography served as notes for me but also became a common effort with the minor to go around finding things that somehow in their view were connected to illness. Minors often 'took over' the photography in the sense of alerting me to what I should photograph. The front picture of this thesis is one such photo that I took when a minor showed me how he practiced home treatment on his sister's doll. This boy understood that I was interested in practices and objects that had to do with illness, and therefore wanted me to take a picture of this learning practice. Here I show further examples of photos taken during participant observation with minors:

Image 3 Examples of photos taken with the minors in their homes.


[redacted] [redacted] [redacted]

In hindsight I might as well have enlisted the minors as full co-researchers in the situation, and given them the responsibility of taking photos of what they felt was important, that is making use of 'photo-voice' as a method (Skovdal and Cornish, 2015b). However, I had anticipated that since the minors did not know me, and would struggle with understanding my interest in objects and practices, they might feel pressure to perform a task for which they did not see the purpose. Yet, when I was in the situation of fieldwork, I sensed on the contrary that the attention given to objects and photography reduced pressure on the minors. They themselves did not have to be the centre of attention, which could make them feel shy. While I looked less at the minors and more at objects that somehow mattered to them, they became engaged in telling and showing their relationships with these objects and the stories connected to them. I return to some considerations about this kind of participation, for me as well as the minors, at the end of this chapter. I took short notes during visits and wrote full fieldnotes immediately afterwards, which resulted in around 300 pages of fieldnotes written on computer. These fieldnotes encompassed quotes from the minors, descriptions of their practices, items and housing interiors, and my own impressions, thoughts, and feelings around the experiences of being given a guided tour in their everyday domestic lives.

During the visits I was alone with the individual minors some of the time, while parents and sometimes siblings remained in other rooms of the home. From a research ethics point of view, I was alert to this being a situation of concern for parents, minors, and myself, as I did not know the minors and their personal issues beforehand and they could doubt my intentions. As a way to make everyone feel safe I always kept the door open when I was alone in a room with a minor. This provided a balance, in that the minor could be the main actor of attention when interacting with me, while the parents/caregivers were still close by and were able to listen in if they wished. I did not sense any worry on the part of parents of minors while the minors were on their own with me. In one case a boy was too shy to talk to me, so instead we stayed in the living room with his mother and sister. I think that my being a young woman that could introduce herself as a mother meant a great deal in terms of assuring parents and minors that I was trustworthy to treat the minors with respect and concern. Yet I did sense that parents were a bit alert to what questions I would pose, and whether I would direct attention to issues that the minors connected with bad experiences or future challenges in connection to their illness. There could for instance be a worry that I would address the issue of a minor's ability to self-inject, while the minor felt a fear of this scenario. However, I felt that I had been informed of such hardships by the parents when we initially talked about their life with the illness. Parents were generally helpful in telling me upfront what hardships they had. Therefore, I never pushed for talking about subjects beyond what the minors were comfortable with. I knew I should not encourage more worry. I will reflect more on in this in the next section of considerations. But I did not stop them if they themselves felt like addressing some of the issues in their own way, and in some cases the minors started explaining their fears or worries, even though those issues had been flagged by a parent for me to be cautious about. It seemed to me that these minors could categorise me as someone that did not have any preference for whether they were good or bad at something, afraid or brave. It seemed that they talked freely, even about hardships. Furthermore, I could sense that most of the parents were curious about hearing what the minors expressed when talking with me without their physical presence. By the end of my visits parents often expressed surprise at how their children had expressed themselves and appreciated being able to be the ‘fly on the wall’, or here ‘a listener outside the room’, as they did not often get the chance to hear their child reflect on illness matters without it being in relation to themselves. Furthermore, the parents’ surprise at hearing how their children spoke about illness was something that alerted me to later consider minors’ and parents’ perspectives as being different and situation-dependent.

Considerations of research with minors

To put it bluntly, I regarded the minors as experienced and skilled persons with whom I could explore their practices, materials, norms, values, and logics, involved in specific situations of their lives. Similarly, the ethnographer Christensen (2004), who has had many years of experience with research with minors, advocates for seeing children primarily as fellow human beings, not in principle to be treated differently from adults. That said, before, during, and after fieldwork I reflected on and adjusted methods accordingly with considerations of the minors’ particular circumstances, which I will outline in the following.

When researching minors’ lived realities there are crucial issues to consider. First, an important point in research with children is the power and status relationship. There is an obvious power relation issue around the position of an adult with a child (Morrow and Richards, 1996; Christensen, 2004). On the other hand, an over-protective position towards children can decrease their freedom and ability to participate in a study (Morrow and Richards, 1996). The task is to ‘redress the power imbalance between the child participant and the adult researcher, in order to enable children to participate on their own terms’ (Nigel Thomas, 1998, p. 23). I tried levelling out the power distribution initially by asking for minors’ signatures and consent to participate in the study, after explaining my aims, methods, and anonymisation strategy. I did this before asking for the parents’ consent and signatures. Furthermore, by positioning myself as a learner of their illness and practices, I came to see them as equals if not superior to me in understanding their illnesses. I deliberately pronounced their diagnosis or treatment with a lack of confidence, to signal that I was not a medical specialist and that I was in the process of learning what their illnesses were about. I sought to make it a common effort between the minor and me to explore how illness related and did not relate to the things, situations, and schedules of their everyday lives. I sought to take the minor seriously as one of the main actors in situations that had to do with their illness. This seemed to work well, as most children were genuinely baffled but accepting towards my lack of familiarity and appreciated my interest in their illness and daily lives, where they seemed to find themselves capable of helping me evolve my understanding of their experiences with illness. Additionally, this positioning of myself as a visitor into their worlds helped me familiarise myself with minors' vocabulary and formulations (Christensen, 2004). Together we looked at the places and procedures for treatment, for leaving the house to go to school, for packing school bags, for being on social media, for lying in bed suffering from pain, for distracting oneself from symptoms, and for practicing self-management.

Another point that needs consideration in research with minors are the consequences of addressing certain issues with which the minors might then be left alone afterwards. I was attentive to this and raised such issues with parents if I was in doubt. It was my genuine impression that my visits started reflection among the minors about how illness shapes their lives, but at the same time increased their awareness of their own courage, creativity, capability, and network of support in handling illness in everyday life. Though some conversations with minors were emotional I am confident that the minors felt fine afterwards and felt listened to, which some explicitly stated.

From a general research ethics perspective, it is furthermore important to consider where research places the subject group afterwards. Kane et al. (1998) is for instance concerned with how research gives back something to the community, or here the population of minors that live with chronic illness, and this is of interest especially when conducting research with children. By thinking about this during my study I have been reflecting on how to avoid my findings and empirical material being used to legitimise new digital interventions for this group. What I aim to give back to the minors that participated in my study, and the general population of minors that live with chronic illness, is an increased recognition of their specific values, norms, work, and continuously evolving practices in caring for their realities with illness. Their realities are not easy to negotiate, but they do what they can, given the particular settings they are positioned within. I certainly did not mean to convey all this in order for minors' work to be exploited for further individualising self-management responsibility. It seems crucial that I express this explicitly. Rather, I wish to nuance debates about minors' ways of living with illness. As a more concrete way of giving something back to the families that took part in the study, I sent to them an article that I had written in layman's terms which I published in a patient society magazine (see Appendix). Furthermore, I offered to put the minors in contact with one another, if I thought they would have a mutual interest in discussing their lives with illness. I also presented my preliminary results at an event at the Danish Haemophilia Society.

Another point to consider is that, as with all groups of research subjects, there is a risk of homogenising and decontextualising (Brady, Lowe, and Olin Lauritzen, 2015). Contextualisation is especially important for my study's methodological reflection as I turn to the lived realities of minors rather than minors themselves as central subjects. I aim to contextualise the phenomenon of living with chronic illness for minors. This is an attention to their settings: the structural, material, technological, and social interrelations that constitute how they are positioned, practice, and perceive their own realities. However, this also implies listening to what minors say and noticing what they do. Scholar have noted that in research with children there are various perspectives on children and childhood that the researcher can take. For instance, one can pose perspectives on the 'developing child', the adult child', or the 'social child' (Nigel Thomas, 1998). In this line of thought my perspective is on the 'socio-materially entangled child' and the 'structurally positioned child'.

Regarding the risk of homogenisation, I see it as a challenge in my study to account for variation, as my aim is to point to how minors as a group share particular circumstances that make them a distinct, and marginalised, group in mHealth innovation. Yet, it should be stated that within my group of minor research participants there were different personalities, preferences, interests, family structures and backgrounds. One lived alone with his aunt. Some loved being the centre of attention. Others wanted to go more unnoticed. One liked fashion, others computer games, another one nature. Some found it cool to have a diagnosis while others detested it at certain times. The participants lived across geographically and demographically diverse areas of Denmark. Some families were settled in managing the illness while others found it persistently difficult. Some families suffered from the traumatic experience of forcing the minor to be injected. Furthermore, everyone had some issues that they struggled with besides their illness. One minor had a cochlear implant. One had a mental diagnosis. Two were bullied at school. Two had bad allergies. One's parent had had a serious work accident. One had been exposed to abuse.

I felt great sympathy for all these, often heartbreaking, stories that were frequently interrelated with how the minors and their families experienced and lived with their illness. This made me realise that ‘illness,’ as the experience of a chronic condition, is complexly entangled with other issues. The interrelatedness of life and illness, in the ‘patient-centred’ perspectives in healthcare, thus make sense. However, it also appeared to me that how these interrelations were shaped depended on the specific situation of participant observations with me. Whether and how battles in the minors’ lives could be related to illness was situation-specific. I expand on this in Article Three. Regarding homogenisation it is thus important for me to have stated the variations between the participants of the study, while in this thesis I aim to point to common mechanisms for how minors establish practices and perceptions of illness, and how they are positioned in relation to mHealth innovation.

On a final note, the points outlined above about what minors and their families shared with me also give rise to reflections on the ethical responsibility adults have towards minors. If witnessing misconduct towards children, one is liable to act. Regarding the minors that expressed experiences of bullying and abuse, I was responsive to what the minors were telling me, and I made sure that the situations were being handled and addressed with parents or caregivers. For instance, a minor that had been abused was safe, had, when I spoke to them, received professional help, and prosecution had been conducted towards the perpetrator. Regarding traumatic experiences of home treatment, in many of the families these stemmed from healthcare professionals prompting of parents to physically force their young children to be injected at home, by holding them down. I talked to parents about this, and some of them took the opportunity of my interest to talk it through. Later I talked to the associated patient society about the issue. The patient society was aware of this problem, was in dialogue with healthcare professionals about it, and assured me that hospital policies had lately been changed so that it is now illegal to restrain minors to inject them. I furthermore learned that a regional knowledge centre for children with pain in Denmark is helping to educate and suggest alternative practices for administering injections without restraint.

Studying technological design in action

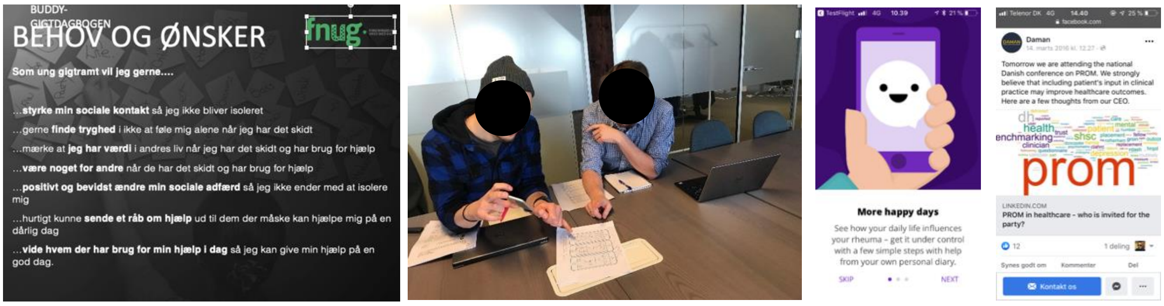
I now outline and reflect on the methods I used to explore the design processes of the two mHealth project cases of my study. I highlight reflections about how to achieve insight into year-long processes, while only being able to observe and be present intermittently over a two-year period.

I conducted fieldwork with the mHealth projects in the period from July 2017 to June 2019. The projects had run since 2013 and 2015, respectively. I therefore missed participating in the first two to four years of the projects. Furthermore, it was far less than every week that I had contact with the projects during the period of fieldwork. It did not make sense to be physically present on a daily basis at the private digital health companies, as the projects were 'lying still' from time to time while the companies were working on other projects. Therefore, there were long periods where nothing happened. Also, the development processes of the mHealth technologies were not only bound to the physical locations of the companies. They also happened in meetings and correspondence with the other stakeholders of the projects. Given all these challenges to following the projects from beginning to end I had to piece together different points in time where the design was emerging, and the user was configured, in terms of decisions and design practices. I had made an agreement with the CEOs of the digital health companies of the mHealth projects that they would alert me when they were having meetings, workshops, tests, developments, or evaluations of the evolving designs. Furthermore, I joined the meetings and presentations for the projects that involved the outside partners of the projects, that is the patient organisations and healthcare professionals and, in the case of the haemophilia project, the regional telemedicine knowledge centres. In addition, I gathered documentation of prior project activities and designs to enable insight into the prior evolution of the design and user-profiles. For instance, the haemophilia project had reports that outlined and summarised all phases of the project, including an initial workshop with minors and parents and user-tests with minors. These materials would serve as empirical evidence alone but were also supplemented by formal interviews with each of the CEOs and conversations with other employees working on the projects, about the design of the apps, design methodologies, choices made, purposes, and evolving user-profiles. In the following I go into more depth about the individual methods for piecing together a fuller picture of the design processes.

Ethnographic trailing of the user during design processes

Through participant observation I trailed the configured user-profile and the evolving design, participating in workshops and meetings where current designs were discussed and altered. I sometimes joined presentations of the technology at innovation conferences, or sat in office spaces and talked with UX-designers and developers, all the time with the interest of knowing about shifts in the designs' functionalities and what profiles of users the involved actors had in mind and the design afforded. I wrote fieldnotes continuously and occasionally took pictures to keep track of how the design and configured user emerged at different times. Here I provide an example of materials collected from the JIA project that enabled me to analyse the development of the design and configured user over time:

Image 4 Example of mixed materials collected with the JIA project. From the left; presentation of needs and wishes of young people in 2013; a photo of developers and a wireframe; screenshot of a suggested app update; a Facebook update on health data work in the digital health company.



BUDDY-GIGTDAGBOGEN

BEHOV OG ØNSKER

Som ung gigtramt vil jeg gerne....

...**styrke min sociale kontakt** så jeg ikke bliver isoleret

...gerne **finde tryghed** i ikke at føle mig alene når jeg har det skidt

...mærke at **jeg har værdi** i andres liv når jeg har det skidt og har brug for hjælp

...**være noget for andre** når de har det skidt og har brug for hjælp

...**positivt og bevidst ændre min sociale adfærd** så jeg ikke ender med at isolere mig

...hurtigt kunne **sende et råb om hjælp** ud til dem der måske kan hjælpe mig på en dårlig dag

...**vide hvem der har brug for min hjælp i dag** så jeg kan give min hjælp på en god dag.

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Daman

Tomorrow we are attending the national Danish conference on PROM. We strongly believe that including patient's input in clinical practice may improve healthcare outcomes. Here are a few thoughts from our CEO.

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PROM in healthcare – who is invited for the party?

Wong et al. (2015) argue that a techno-anthropological study demands reflection on how to position oneself as a researcher in different situations that can be said to be part of the technological innovation process. I participated in the design process in the sense that I offered my perspectives in workshops or conversations when I was asked. I had previously worked with telemedicine in the capital region of Denmark, and with digital health innovation in a pharmaceutical company's innovation lab, where I established the user involvement processes. I had shared this information about myself with the project members. I sensed that this helped open the doors for my participant observation in the projects, as the project members did not see me as one that was opposing digital health development but rather as someone genuinely interested in the field. Taken together with the fact that I was conducting participant observation with their target groups, I increasingly took on the role of 'one that knew something about the users' in the projects. For instance, I was often asked what I thought of the functionalities in the prototype apps. Here I could for instance say that I was starting to become aware that minors have certain preferences about when to attend to their illness and that self-management apps should probably reflect this. I was continuously reflecting on how I was affecting my field. On the one hand, ethnographic fieldwork can never be neutral, and one will always affect and be affected by actors in the field (Keiding, 2011). On the other hand, I was interested in how such projects gain insight into those groups and settings to which they target the design, without conducting fieldwork on the lived realities of minors. I was interested in exploring possible troubles between what the projects assumed/thought/knew about minors and how I had seen minors live with illness. I therefore chose to limit my sharing stories of my fieldwork with minors, and yet tried to participate in the work of the projects by posing questions about what current designs would mean for minors as users. These were questions on which I would like to hear developers' reflections, and the developers appreciated the opportunities to think reflectively about the choices they made during the design process. I sought to find out how the designs, user-profiles, and design methodologies made sense in the design situations – why did it make sense to create this or that functionality in the app? – while at the same time having gained my own insights about minors' lived realities with chronic illness. I allowed myself to have a double attention to what 'minors that live with chronic illness' implies, from the perspective of minors' domestic living and from the perspective of projects. I became aware that the projects' concern implied fitting a technological design not only to patients but also to clinicians, healthcare data systems, clinical practices, safety and security regulations, databases, and economic models. This I unfold in Article Two. I also tried to see things from the perspectives of the evolving technologies. What did they aim for and why? What actors did they depend on to fulfil their functionalities and purposes? I did not feel that I should, or could, 'correct' mistuned perspectives on minors in the projects. Rather, I was there to understand how certain designs, user-profiles, and approaches to minors that live with a chronic illness make sense in the situations of design.

Document and visual analysis

When, during my fieldwork with the two design projects, I found out that they were dropping minors as a target for the solutions, I regrettably thought that I had picked the wrong cases. I had wished to investigate the full design process, from idea to finalisation of an app for minors. Yet this was the reality of innovation of these mHealth technologies. What I came to realise was that this was a piece of good fortune – presenting me with an optimal chance for exploring the troubles leading to this change: A machinery of technological innovation that had some defaults or settings that made it incapable of attuning to minors. It was at this stage that it became clear to me that I had to look specifically at the design practices that led up to the point where minors were excluded as users. I collected materials of prior and present phases of the design processes, including presentations, reports, test-guides, screenshots of prior designs and descriptions, and prototypes that I could analyse. Readings of these materials served multiple purposes in my research. First, I could analyse how the design and profile of the configured user changed over time. Second, I gained insight into the design methodologies and practices of user-driven innovation and how these affected the design and user-profile. Third, I gained insight into how healthcare paradigms of 'patient-centred care' and discourses of 'self-management', 'empowerment', and the like, were impacting on the design. As a final purpose, I could use the materials as points of conversations with project employees about the design history of the project.

This empirical material significantly extended my insight into the projects' interrelatedness with private development companies, the healthcare system, data structures, economic structures, legal structures, paradigms of healthcare, and design processes. It helped me to go beyond 'the knowing subject' of project owners as centred knowers and decision makers and into socio-materially constructed and discursive situations (Clarke, 2005, p. xxix). In line with Clarke's situation-centred approach that suggests to, in addition to studying action, include 'the analysis of the full situation, including discourses – narrative, visual, and historical' (ibid, pp. xxxii) – I paid attention to objects, people, sayings, and discourses in the design project situations.

Semi-structured interviews

The interviews I had with the CEOs of the digital health companies of both projects were meant to contribute to my ethnographic material, with their experiences of the turns that the design had taken since the start of the projects. Furthermore, the interviews contributed the CEOs' perspectives on what led to the exclusion of minors as target users – why it had been challenging to keep this group as a user and attune the design to them. The interviews lasted around one hour and were structured by an interview guide, yet I freely asked more about issues that arose during the conversations. Likewise, the CEOs took the opportunity to ask me questions about my fieldwork with minors, my experience with mHealth and user involvement, and my view on the current projects. As Rubow (2003) argues, interviews can be seen as part of the process of participant observation, and especially the conversation about practices can help elaborate or nuance the observations one has conducted. Though the CEOs at times talked about the projects in very abstract terms and used a lot of jargon, in the interview situation we could share perspectives and become mutually interested in the challenges and the practical circumstances of designing mHealth.

In consideration of the stakeholders in the mHealth projects I asked the CEOs to read through Article Two. Furthermore, we reached a mutual understanding that I would not be able to anonymise the projects – they would be identifiable through a simple search on Google. At the same time, we had agreements on what I could disclose in the articles and thesis regarding their businesses. I also considered how to avoid showing the projects and the private digital health companies in a negative light. In my opinion the in-depth descriptions of the projects explains the employees' ways of acting. Therefore, I found that I could take a critical stance, not towards individuals or individual institutions, but rather towards the interplay between actors in mHealth innovation and how this interplay comes to marginalise minors as a group.

Studying minors' and parents' perceptions through focus group discussions

In this study I found it crucial not merely to ask for minors' views on illness and mHealth. This is the reason why I conducted the participant observations, as outlined earlier. Yet, after I conducted participant observation with minors and the design projects, and started analysing the empirical material, I found it important to also explore minors' *perceptions* of illness in relation to self-monitoring. This is because I had witnessed minors' preoccupation with keeping illness-related practices to the domestic space and to a large extent out of their interaction with peers. Furthermore, parents had voiced how the families wanted to limit how much attention the illness was given in their lives. When it became apparent to me that the JIA project were designing their solution accordingly with whole person or holistic perspectives on illness monitoring, I reviewed the minors' ways of expressing their perceptions of illness as possibly contrasting this. I found it important to take minors' ontological perspectives on the relation between illness and their lives in general into account. I wished to explore how various kinds of measures for life with illness (e.g. symptoms and mood) were something that minors and their parents could see themselves attending to. I therefore arranged focus group discussions separately with minors, parents, and a hospital youth panel to explore how their perceptions on life with illness were formed, and how they could relate to mHealth self-monitoring.

Focus group discussion is a qualitative method for producing empirical data at a group level (Morgan, 2012). 'Focus' implies the involvement of a collective activity in the discussion (Kitzinger, 1994) to seek out group interaction about the issue of concern (Merton, 1987; Morgan, 2012).

Levine and Zimmerman (1996) argue that focus groups promote independence from the researcher among the participants, which raises their level of openness, confidence, and impulsiveness. The researcher's role in the co-construction of meanings and opinions is less influential on the group (Lehoux, Poland and Daudelin, 2006). Thereby the discourse of the group is less oriented towards an 'outsider group' and more towards the group itself (Bourdieu, 2020). Focus group discussions can thus be fruitful for generating insight into shared beliefs and experiences among a group that have something in common, and that see themselves as constituting something different from outside groups. It provides insight into tacit assumptions that prepare the ground for the groups' way of behaving (King and Horrocks, 2010), which is exactly what I looked for in exploring what assumptions, views, and reasons lie behind minors' attitudes towards mHealth, illness, and life in general.

The focus group discussions with minors, parents, and young people would not alone enable insight into what constitutes minors' lives with chronic illness. My use of the method must be seen in light of the participant observations I undertook in minors' domestic lives, and in mHealth design projects' purposing of mHealth. Without attending to the practical and socio-material settings that orchestrate minors' everyday domestic lives I would not have been able to see the interplay between how life is something that is lived and experienced. Focus groups cannot account for what people and things actually do and how they interact, because settings, structures and practices are often so embedded into life that people do not think about them. Participant observation on the other hand cannot account for how people perceive a phenomenon, how their opinions can be challenged, or what norms are applicable in the social interactions – focus groups enable this. Carrying out both participant observation and focus group discussions allowed me insight into both practices and perceptions of illness with minors. These insights I could then compare with notions of 'self-management'-practices and illness-perceptions that were being inscribed into the mHealth designs.

I reasoned that the perceptions about illness and the everyday life of minors should be seen in connection with parents' perspectives, and in light of how young people later review ways of perceiving illness. Through focus group discussions I sought to generate knowledge about minors' and parents' perceptions, experiences, norms, and values concerning illness in relation to everyday life. I therefore arranged one focus group discussion with minors living with haemophilia, and three groups with parents of minors living with haemophilia. An apparent limitation to my study is that I did not manage to arrange focus groups with minors living with JIA and their parents. Due to a lack of response from the patient society for young people living with JIA and a lack of time in my project I had to accept not including this group in the final fieldwork stage of the study. I link two considerations to this. First, the patient society seemed much stronger and members more attached in the case of haemophilia compared to the patient society for JIA. I gained this impression when trying on various occasions to communicate with them to ask them to serve as gatekeepers, to allow me to participate in events, and to offer them insight into my findings. The present head of the JIA patient society had personal challenges at the time and there was no one else to take over the responsibility of communicating with me. I am sure this was due to a lack of resources of the patient society rather than lack of interest. The second point that needs addressing is that because I did not represent minors living with JIA through the focus group discussions, I assume that I missed representing a population of minors that perceive their illness somewhat differently to those living with haemophilia. I hypothesise that minors living with JIA have less of a community feeling, and struggle more with legitimising their felt experiences of the illness, than those living with haemophilia, due to how people at large regard the two diagnoses. I built this hypothesis on articulations of minors about other people's views on them from my participant observation with both groups. Though I missed the JIA focus groups in my study I tried levelling out the attention to one specific diagnosis by inviting the Danish hospital youth panel for a focus group discussion. This panel consisted of young present and former patients with a variety of diagnoses who were around the ages of 18 to 25. I thought it important to bring in their views because they would have fresh memories of being minors living with illness, while at the same time being used to discussing and expressing their opinions and experiences. Because the members of the youth panel represented various different diagnoses they helped in illuminating differences of struggles and legitimisations of disease-related experiences and perceptions, as I unfold in Article Three.

The one focus group discussion with minors living with haemophilia, and the three focus group discussions with their parents, were carried out in September 2019, and the one focus group discussion with the youth panel was carried out in June 2019, all discussions lasting around an hour. With the focus groups I constructed situations for discussion of mHealth on a phenomenological, normative, and experiential level with parents, children, and young people that live with chronic illness. I chose three different collective activities and accompanying stimuli for engaging minors, parents, and young people, respectively, in discussion about how to perceive illness in relation to everyday living and use of mHealth monitoring of illness experiences. I therefore provided discussion stimuli appropriate for each of the groups.

For parents, the stimuli consisted of statement cards (Kitzinger, 1994) about condition management in everyday life with and without mHealth. This initiated discussions about treatment, communication with healthcare professionals, normality, how much space the condition takes up, and practicalities. I was not present when the parents talked together, because I was simultaneously facilitating the focus group discussion with their children in another room. Instead, I left instructions and a voice recorder for each group, after introducing my research interest in person. Leaving parents to talk together worked well, possibly because most of them knew each other through The Danish Haemophilia Society, but also because they could try to work out what the statements implied and could freely express themselves without having to take me into account. A disadvantage however, was that I had no chance to ask for elaboration when they touched upon issues that I found particularly interesting.

At the focus group with the children I had, with inspiration from Clark (2004), arranged visual stimuli in the form of pictures related both to medical treatment and to objects and elements of everyday life, like a syringe, football, school; but also physical objects actually in the room such as playdough, coloured paper, scissors, and so on, to play with or use to make arguments. The stimuli were to signify the children’s realities, in which specific materials and technologies matter (Koch at al., 2011), so that I would be the visitor to their worlds when, together, we discussed a series of fictional child characters and their challenges in living with haemophilia, that I had prepared. As the vignettes were built on observations of the minors that I visited during participatory observation, I assumed that the children in the focus group would recognise them and bring in their own experiences and thoughts to continue the stories. The characters and challenges were outlined as short open-ended vignettes (Barter and Renold, 2000), to be continued in group discussion. At the end of the session, I presented vignettes of two groups of fictional children who were creating both the worst and the best ‘haemophilia app’ they could imagine. Discussing the worst possible app had the effect that everyone could join in without fear of saying something stupid, and it prepared the ground for afterwards discussing what a 'good' app would be. Nieuwenhuys (1996) has argued that activities such as storytelling enable complexities of experience to be brought out, and I found that the children easily joined in with the stories and responded to what others said. Furthermore, the fact that discussion centred around characters similar, but not identical, to themselves, offered freedom to verbalise perspectives independently, yet informed by their own experiences (Metatla et al., 2020).

With the young people's focus group, I introduced a series of discussion points regarding both experiences in living with a chronic condition and how mHealth could possibly assist or counteract living with these experiences. In general, the young people took the lead in the conversation (especially the three young women), introducing points important to themselves. My part became one of drawing out their elaborations and exposing differences in their views when they touched upon living, digital condition management, normality, and different approaches to experiences of living with their conditions.

Participation

I have until now termed myself a participant in minors' lives through participant observation, but also termed the minors and parents as participants in my study. I here share some thoughts on participants and *participation* in relation to my research.

I saw myself first and foremost as one that participated in minors' practically and perceptually lived realities. By focussing on my own *participation* in minors' lived realities and in design processes I tried steering my gaze towards the socio-material assemblages of interaction around minors' realities with illnesses, rather than placing the minor as a participant in my study. Seeing myself as a participant in different situations and sites helped me keep an openness to the priorities and agendas of those that I explored (Christensen, 2004). While I was the participant, I was up for exploring the agendas that both minors and designers had, concerning the issue of illness management. 'Participatory research' connotes studies where human respondents are freer to define the research agenda (Clark, 2004). Though my study is not such an action- or community-based research project it contains elements of detecting and converting into knowledge what minors articulate and show as values in living with a chronic illness, and their reflections on mHealth technologies. I do not claim to 'give minors a voice' but rather to convey their socio-material practices and perceptions in their lives with chronic illness. Purposing to 'give voice' (cf. my earlier attention to how participatory approaches can be used to fulfil political and strategic purposes) risks serving as a scapegoat for carrying out research agendas that are really decided by the researcher (or designer). This has also been referred to as 'tokenism' (Clark, 2004). I have aimed to frame my methodological ambition as trying to recognise agency/action/socio-material embeddedness. Such a notion does not pretend to capture a neutral reality of minors and is not limited by what minors are capable of articulating or agreeing to. It rather acknowledges that my study has a continuously evolving research interest that the minor, the mHealth project members, the empirical socio-material fields, and I, myself, have worked together in informing.

Limitations of the study

I will here outline and reflect upon the limitations of my methodology. First, the study is limited in not exploring minors' lived realities outside of the domestic setting. It is possible that participatory observation of minors in school and leisure time settings would provide insight that furthers what they expressed in phrasing and practice in their domestic settings. Second, my participatory observations during the visits were limited to a single visit of a couple of hours. This means that I did not have the chance to see practices repeatedly, and how they evolved over time. Third, there is the limitation that I did not follow the mHealth projects from the beginning. This has prevented me from participating in phases where minors were involved in ideation and so I have solely relied on documents and employees describing these phases. Furthermore, it has prevented me from practically exploring prior design methods, designs, and accompanying user-profiles, apart from mock-ups, wireframes, and screenshots of earlier version apps that I collected. I have thus encountered some blind spots in my study, for instance of how minors explicated their experiences, opinions, and ideas in the initial phase of the projects. Fourth, the projects did not only target minors but also adult patient groups, which limits the generalisability of my findings. This is because the incentives and resources for continuously ensuring that the design targets minors might be larger with projects that solely focus on a minor target group. Fifth, there were limitations to the focus groups' discussions. These mainly revolved around the fact that I asked the groups to discuss imaginative scenarios of illness monitoring. The participants thus did not discuss from experience with actual apps. What they discussed thereby does not reflect how they would understand and use an mHealth app, even though the imaginative scenarios drew on real app functionalities of the two mHealth projects. Yet the discussions of the scenarios generated insight into how the participants form their perceptions of illness in relation to monitoring it, which are interesting and can be discussed against the way mHealth projects attend to illness.

To summarise this chapter, I return to my setup of a double-sited ethnography. This methodology allowed me to study illness self-management across the sites of minors' lived realities and mHealth innovation. More specifically it enabled insight into, on the one hand, minors' particular circumstances for living with chronic illness, and on the other hand, how mHealth innovation attunes the designs to minors' particular circumstances. I have argued that multiple methods enable multifaceted insights into attuning of mHealth design. My methodology enables not only converting what minors' need, or what mHealth projects think is needed, but makes it possible to explicate the complexities and situatedness of what 'illness management' implies in both ethnographic sites. It allows me to see the situatedness of both sites' way of working with illness management and stay with their troubles in relating to one another.

4. Data and analysis

Because this study was conducted by means of multiple qualitative methods my dataset is diverse and wide. Below is a table providing a full view of my data materials and how they have prepared the ground for the three analyses of the respective articles of this thesis. Following the table, I will outline my analytical process.

Table 2 Overview of data generated in the study

	Field notes	**Transcripts**	**Gathered materials**
Analysis of minors' practices of illness (for Article One)	Participatory observation (around 300 pages) and photographs (around 100) of minors and family members		
Analysis of mHealth design processes (for Article Two)	Participatory observation (around 150 pages) and photographs (around 30) of both mHealth projects, including regular conversations, workshops, tests, evaluations, presentations, and various meetings	2 interviews of around 1 hour duration with the CEOs in the projects (around 30 pages of transcripts)	Funding applications, newsletters, public announcements, presentations of the JIA project (around 50 pages) Screenshots of JIA app design over time, and promotion on Facebook and LinkedIn (around 70 screenshots) Presentations and written documentation of all phases in the haemophilia project (around 300 pages)[6] Screenshots of haemophilia app prototypes (around 10 screenshots)
Analysis of minors' perceptions of illness (for Article Three)		1 focus group discussion with minors around 1 hour (12 pages transcript) 3 focus group discussions with parents around 1 hour (30 pages transcript) 1 focus group discussion with youth panel at hospital around 1 hour (10 pages transcript)	

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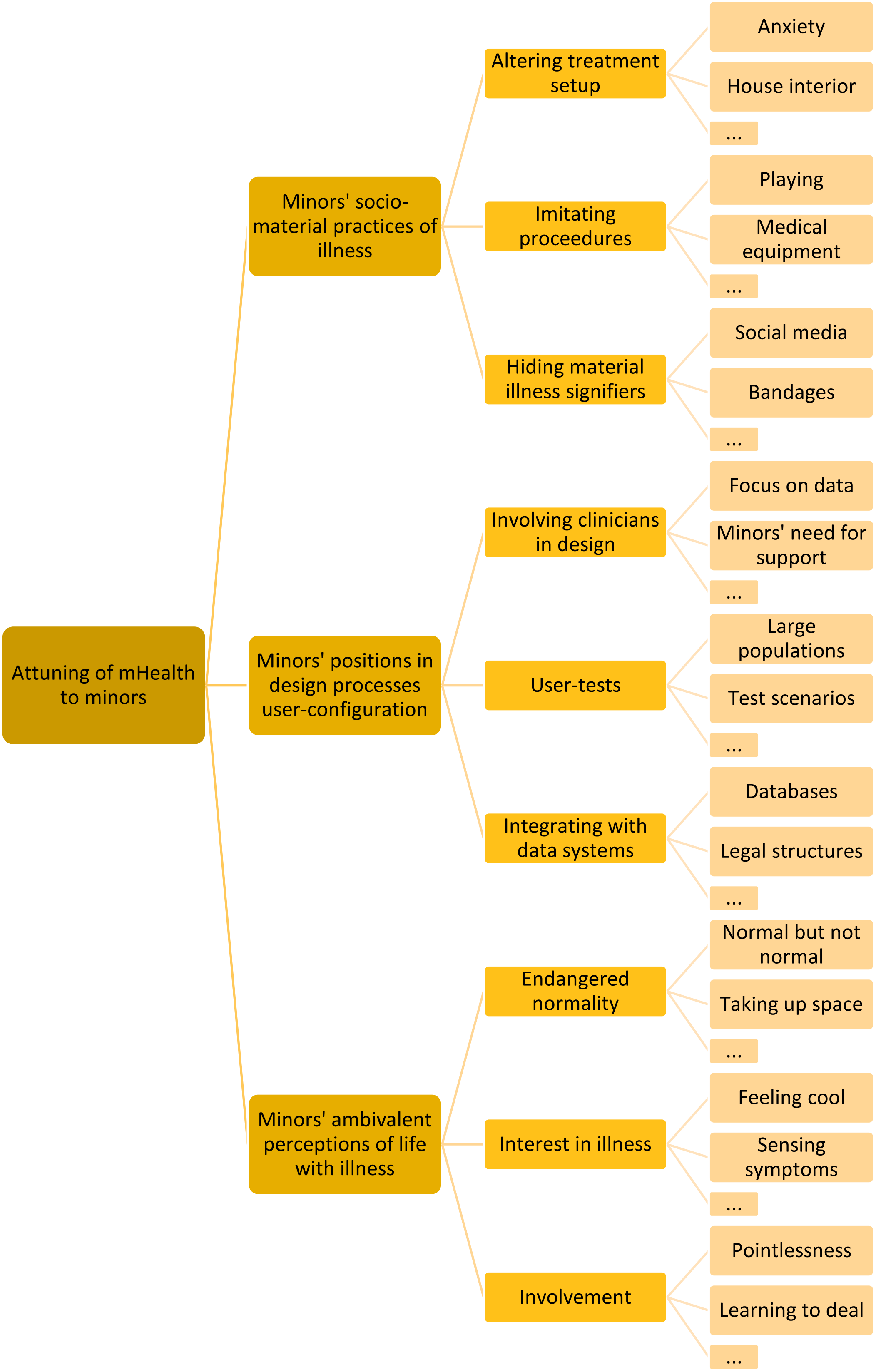
[6] Documentation by the hemophilia project of the different design phases are available to the public and can be found via this web-link: **https://www.rm.dk/sundhed/faginfo/center-for-telemedicin/projekter-og-indsatser/Beslutningsstotte-i-bloderbehandling/Dokumentation/**

Analytical process

I have considered all my data as ethnographic data that I have coded with the aid of the software NVivo 12. Using NVivo helped me to first organise three sets of data (one for each article as seen in the figure above) that I could code separately. Later I was able to consider how each set's emerging themes spoke to an overall theme of the relationship between minors and mHealth. I thereby carried out three rounds of data analysis after my fieldwork in the homes of minors, in the mHealth projects, and in focus groups with minors, parents, and the youth panel. However, the final round of analysis of minor's perceptions of illness was, as stated in Chapter 4, much driven by the analysis I had already done in the two previous rounds with minors' practices and mHealth design. My attention was drawn to the connectivity of illness and daily living in the final dataset. I had an eye on terms like 'normality,' 'differentness', and situations where illness was something that minors attended to or not.

As a point of departure for all three rounds of analysis I have used a thematic network analysis strategy as developed by Attride-Stirling (2001). In each round I organised the associated datasets into first 'basic themes', then 'organising themes', and lastly 'global themes' (ibid). This means that each round of data analysis can stand alone and has formed the basis for an article: Article One about minors' practices of illness management, Article Two about minors' positions in the design process, and Article Three about minors' perceptions of life with chronic illness. The separate analyses are outlined in the associated articles. Each analysis furthermore contributes aspects to consider under the collective theme of this thesis – troubled attuning of mHealth innovation to minors' lived realities with chronic illness. Below I present an overall visualisation of how I grouped each dataset into themes and how they interrelate in the framework of the thesis.

Figure 3 Overview of data analysis in steps (from right to left) of basic themes, organising themes, global themes, and lastly the overall theme of the thesis.



While I organised the empirical material into networks of themes (Attride-Stirling, 2001) this was done with attention to how human and non-human actors formed relations. Following the situational analysis approach, I paid attention to ongoing relation-making and contradictions between human and non-human actors on societal, organisational, institutional, and discursive levels (Clarke, 2005). As part of my analysis process, I looked across the datasets, and thus ethnographic sites, and for instance analysed pictures of mHealth prototypes against parents that repeatedly stated that illness should not 'take up too much space' and minors' practices of illness management. I furthermore looked across the two app designs and across the groups of minors living with JIA and haemophilia. I re-read my material again and again. I continuously drew field maps of various actors, their mutual connections, and different situations throughout the period of fieldwork and data analysis. For instance, I explored how the terms 'normal' and 'illness' related across various situations that minors were engaged in. I saw contradictions between mHealth innovations' attention to connectivity between illness and everyday living and minors' ambivalence towards attending to their lived experiences of illness.

My inspiration from feminist STS grew during the analysis as I discovered that there were discrepancies between how minors live with illness and how mHealth innovation pictures that they live with illness. When I, in the last phases of each analysis, became clearer on how theoretical approaches (*socio-materialism, user-configuration, ambivalence*) spoke to my emerging global themes, I wrote many sets of memos and drafts for the final analyses. This work of abductive analysis (Timmermans and Tavory, 2012) consisted for me in repetitive readings of theoretical concepts and in returning to my thematic network analysis. Going back and forth between my material, memos, theoretical articles, and map drawings helped me put into words what characterises minors' lived realities with illness and mHealth design processes, and the ways of attuning and not attuning the design accordingly with minors. The global themes that I ended naming the 'practices', 'positions', and 'perceptions' became a way of categorising points of concern of minors' lives with chronic illness in relation to mHealth.

On a summarising note, the empirical materials were collected with the overall aim of exploring how minors' lived realities with chronic illness are reflected in mHealth innovation. However, I sought to be open towards my material during analysis. This openness concerned words, phrases, and images, that seemed to differentiate accordingly with the situations in which they appeared. I became continuously more alert to discrepancies between the situations of minors' lives and mHealth innovation during the process of analysis. That said, this openness was accompanied by my research interest in STS and my gaze during fieldwork and analysis has been drawn to relationships, objects, practices, structures, and agendas, and the frictions between these, which allow me to stay with the troubles of attuning mHealth to minors.

5. Discussion of results

Take one for the team
You're a cog in the machine
It's like a default

[…]
You took part in the race
But disappeared without a trace

[…]
Forget about the cause
Press rewind then stop and pause
It's like a default

Selection of lyrics from the song Default by Django Django, 2012.

I now present the results of each article. This provides insight into minors' particular circumstances regarding illness management practices, position in technological design processes, and perceptions of living with illness. Afterwards I interpret and discuss under the term *troubled attuning* how these findings provide interesting new perspectives on mHealth innovation with minors. I argue that my troubled attuning approach provides new angles on the mixed evidence of mHealth's effects on minors that live with chronic illnesses, and I state the thesis' contributions. Lastly, I conclude how the analytical results answer the thesis' research question.

Recognising minors' socio-material engagement in care and management practices

In Article One my co-authors and I show how minors actively seek to affect how their illness and treatment is managed, seek out management learning, and care for their own normality in the realm of everyday life. Through the concept of socio-materiality we argue that minors engage as crucial actors in establishing self-care and self-management practices, but in their own ways and to accommodate their own comfort, learning, norms, and values. Their illness management is neither determined merely by caregivers nor by technical instructions. It is established over time through collaborative involvements, repetition, and alternation of a home treatment management script. This script is continuously developing through the engagements of minors, parents, smartphones, housing interiors, treatment devices, and timeframes and phrases. We show how minors seek to affect the script of how home treatment is carried out. The minors make demands and suggestions. They are engaging even when subjected to injections, because they develop their own strategies for partaking in a way that makes them comfortable. They may, for instance, distract themselves and recite a countdown before the parents do the injections. Minors' acceptance of the home treatment script to a large extent depends on their own engagement in trial and error processes of finding the treatment script that works best. We further show how the minors stage 'imitation games', which is play where they can try out various practices, narratives and distribution of roles for treatment management. These imitation games help minors evolve perspectives on how to take on more illness management responsibility and tasks, and to imagine themselves as taking on the role of being both the treat*er* and the treat*ed*. Lastly, we show that minors attempt to keep illness-related practices and objects to the domestic space and out of non-domestic spaces. Though illness signifiers, like treatment equipment and symptoms, might flow into other spheres than the domestic, for instance at school, the minors try to tactically hide signifiers of illness from online and offline spaces of social interaction, especially with peers. On some occasions however, minors can feel the need for outsiders to show concern for their illness and can in such cases tactically increase attention to it by revealing illness signifiers. We conclude by arguing that the minors' socio-material self-care practices help them make sense of their illness, their treatment, and the variety of treatment roles that they might be able to take while also enabling their gradual independence. We further claim that the agentic capabilities of minors to engage in managing their illness reveal practices, concerns, and norms that are vital to consider in research and practice that is related to chronically ill adolescents' transition to greater treatment responsibility and independency.

Recognising minors' positions in data-driven design processes

In Article Two my co-authors and I tell the design stories of the two mHealth projects. The projects initially aimed to target their designs at minors living with haemophilia and JIA, respectively, as one of their target user groups. Yet, both projects ended up with final apps that only adult patients could use. We explore what led to this exclusion of minors as a user group. Our analysis shows that the projects were initially concerned with minors' particular inexperience with and need for assistance in, producing, reading, accessing, and reacting to health information. However, the projects drifted towards concerns with quantities and qualities of data and with data systems. By aid of our critical user-configuration perspective we attend to how various design practices increased a focus on data, which came to demand of users a certain position towards their own health data. Particularly, in three moments of the design process we see the drift towards data intensify. These moments are where the projects expand the group of prospective users to include clinicians, where subjects are selected for user tests, and where digital health infrastructures are informing the design process. In these moments, we argue, the user is configured in terms of their ability to be a 'data provider', be 'data-proficient', and be 'data-compatible'. The drift towards data causes a cumulative exclusion of user types that are less datafiable – that is, minors. Issues about minors' particular dependency on support for producing and reading health information *did* turn up during the design processes. Yet, the mHealth projects failed to align the design and accordingly the configured user with these positions. Both projects increasingly focussed on adult patient positions towards health data. We argue that the failed alignment to minors' particular positions towards health data must be seen in light of the projects' dependency on and embedment in technical infrastructures, data systems, clinical practice, data-reliant economy development strategies, juristic categorisations, and safety and security structures. The projects could not freely align the design with minors' particular, less datafiable, positions. Against this background we conclude that there are moments in the supposed 'user-driven' design processes that are critical for determining who can become a user. mHealth user-driven design methodologies are drawn in the direction of data-driven methodologies because of the health data purposes and structures in which the projects are embedded. We show how these data-driven design methodologies come to incorporate barriers for sustaining minors as a particular user group throughout the design process because of minors' particular positions in relation to health data.

Recognising minors’ perceptual ambivalence towards ‘living with’ chronic illness

In the third article I am interested in understanding how mHealth-enabled monitoring of patients’ experiences in ‘life with illness’ relates to the ways in which minors perceive chronic illness in relation to their everyday lives. I outline that mHealth innovation can apply various monitoring measures for chronic illness. The approaches range from merely measuring symptoms and treatment to including a wider range of ‘subjective’ or ‘holistic’ measures, such as mood and feelings, and how these relate to the condition. A common feature of the various mHealth illness measures is that they seek to generate insight into patients’ experiences of how their illness influences their daily lives and vice versa. This is how illness and life are interconnected. Thus, mHealth reflects a ‘patient-centred’ healthcare perspective – an approach to how ‘living with’ chronic illness is experienced and can be improved. In this article I enable focus group discussions of what the various functionalities and monitoring measures of the designs would imply for the minors’ and parents’ perception of their illness in everyday life. The focus group discussions render insights into minors’, parents’, and the youth panel members’ perspectives on attending to the interconnectedness of illness and everyday life, through monitoring of their various experiences with the illness. The discussions reflect the ways in which minors, parents, and youth differentiate between which experiences of illness to attend to, accordingly with the situations they are in. They often delimit attention to their experience of illness because they are in a situation where such attention does them no good. For instance, all three groups try not to direct too much attention to experiences that increase feelings of differentness, sickness, or being affected or limited in everyday life, especially in interactions with peers. In other situations, they find reason to increase attention to illness experiences that they feel can inform their practical condition management. This is mainly in delimited domestic situations where they evaluate treatment and triggers of symptoms. I direct an analytical attention to the ambivalence that lies in minors’, parents’, and young people’s attention to illness in aspects of everyday life. I argue that they in different ways voice a need for controlling and limiting their attention to the connectedness of illness to their everyday lives. They must detach from it in certain situations. I argue that in contrast to ‘living with’ illness, minors need the flexibility to sometimes see themselves as normal, that is disease-free, and at other times attend to how the illness works in their lives. Thus, they live *ambivalently* with illness. I suggest that mHealth monitoring of a wide range of ‘patient experiences’ of how the illness effects and is affected by living might potentially prompt minors to direct more attention to how illness connects to numerous aspects of their lives. In this respect mHealth-enabled monitoring of patients' experiences of living with illness can come into conflict with minors' freedom to choose *when* to focus on *which* illness experiences and thereby their values in experiencing part of their living as normal.

Troubled attuning of mHealth to minors

In the following I discuss how my findings give rise to new perspectives on mHealth innovation's relation to minors – or rather mHealth innovation's *attuning* to the particular circumstances of minors. In music, *attuning* accounts for the process of bringing something to resonate with something else to constitute a harmony (Online Etymology Dictionary, no date). In psychological therapeutic contexts, attuning implies the sensing of specific people and the learning of their rhythm, affect, and experiences. Sensing and knowing allows opportunities for creating connectedness and achieving a resonating response with someone (Erskine, 1998) – or with something. I use attuning as a metaphorical framework to discuss the capabilities in mHealth innovation to recognise and resonate with the particular circumstances that make up the orchestration and rhythm of minors' lives with chronic illness. Attuning draws attention to the orchestration of people and things rather than merely to individuals. Furthermore, *troubled attuning* will serve me in describing mHealth innovation's (in)ability to recognise and resonate with minors' lived realities. I direct attention to mHealth innovation's mistuning to the complex realities of a particular target group while the technology is in the making, and to otherwise overlooked structural defaults in the field of mHealth innovation. My attempt to trouble and stay with troubles in the attuning of mHealth to minors' lived realities helps in exploring otherwise unquestioned structures, methods, and purposes of mHealth innovation. My *troubling* of the matters does not necessarily imply a call for 'solving' the challenges that arise when minors are made the subject of mHealth innovation. By recognising that a striving to do away with 'the difficulties' of how minors live with and manage illness can lead to other unintentional consequences of (well-intentioned) interventions, we might instead seek out opportunities for living with experimental learning, socio-material collaboration, and ambivalence.

More specifically, the following discussions imply looking across the three sub-studies presented above and relating their findings to the literature reviews presented in Chapter One. A theme across the discussion points is my troubling of mHealth innovation's pervasive attention to the (adult) *individual*. That is, the purpose of mHealth is to increase patients' *self*-management, the method for designing mHealth is *user*-driven innovation, and the healthcare paradigm permeating mHealth is *patient-centred.* On an overall level I will argue that, especially when it comes to minors, attention to the individual is troubling because it neglects the situational, structural, and socio-material embeddedness of minors in relation to their illness management and everyday life.

Troubling adultism in mHealth innovation

As outlined initially in this thesis, mHealth innovation focusses on patients as individuals and their capabilities to enact self-care and self-management. Such patient perspectives have transferred to the innovation of mHealth to minors. Furthermore, there is a tendency for mHealth technologies either to address parents as the main actor for managing illness, or to address minors in terms of their future roles as self-managers of their illness. I see these tendencies as expressions of adultism that I will trouble.

Assuming parents as *the* illness manager in mHealth apps

First, attributing management and care merely to the practices of parents would be a neglect of minors' engagement. As demonstrated in Article One, it is not only parents that determine illness management – minors engage too. Minors' do enact active roles in how illness and illness-management is constituted in their lives. These roles might be difficult to recognise as they are hiding in the particular situations of treatment, play, dynamics between parents and minors, housing interiors, and everyday objects in minors' domestic lives. But minors' engagements are there, and they are affecting how management practices are established. In this sense my findings confirm the arguments made by other scholars that minors are not merely conforming to parental will on illness management but developing strategies to deal with and oppose adult-defined agendas (Sawyer, 2003).

This finding gives reason to trouble mHealth projects that emphasise parents as the sole facilitator of illness management. This is because the concerns of minors, their attempts at involvement, their mobilisation of control, their norms, comfort, interest, and playful building of confidence in illness management, would be disregarded if addressing parents as *the* illness-managers of attention. On the other hand, it does make some sense when parents are appointed to this role since (most) caregivers *do* have the greatest capacity to safeguard their children. Within the field of sociology of health and illness, Christensen and Mikkelsen (2008) similarly argued that while adults play active roles in guiding children and protecting them with regards to their inexperience and misjudgement concerning their health, children in general are willing to make mistakes, take risks, and search out solutions as part of a collective learning and self-care.

My troubling of the matter then is not suggesting leaving parents out of the equation. Rather I speak for questioning whether parents can be seen as *the* crucial illness manager, when minors themselves are very much involved in shaping the illness management script. While parents facilitate some aspects of illness management, minors in collaboration and addition attempt to facilitate other aspects, particularly those they consider to be missing in the illness management script. What I raise here is a concern with the tendency of only targeting parents as illness managers in mHealth innovation. This, I argue, undermines minors' engagements in illness management, potentially signalling that minors should not be involved, and leave out possibilities for mHealth designs to acknowledge their agencies and opportunities for collaboration with parents.

Focusing on minors' becoming

Second, focussing on minors' 'becoming' prevents recognition of their 'being'. My findings with the two mHealth projects observed a focus on 'self-management', 'empowerment', and a 'data-capability' that did not resonate with my findings in Article one.

James and Prout (2015) argue that we in general should be more alert to minors' 'being' and recognise their competencies rather than their present immaturity and subjection, in contrast to their 'becoming'. Furthermore, as argued by Birch, Curtis, and James (2007) we should be attentive to how minors differ from adults when considering the design of healthcare services. I find this to be applicable to the case of mHealth innovation with minors in terms of their focus on minors' becoming self-managers and neglect of their present abilities and inabilities regarding illness-management. I found with the mHealth projects an incapacity to expose and inscribe into the design minors' ways of engaging, experimenting and learning about illness management. They assumed that mere 'data overviews' of correlations between treatment, symptoms, triggers, and everyday experiences of illness makes patients change their behaviour. How exactly overviews of data would bring about an increase of illness self-management was never really debated in the projects. Likewise, Beacham and Deatrick (2015) find that little progress has been made in informing illness management interventions about minors' existing agency and co-constructions of their realities. My study confirms this with the cases of mHealth based interventions for this group. I thus raise the point that the process of how minors go from illness monitoring to changing illness management behaviour was largely assumed in the mHealth projects. Furthermore, I find that there seems to be a gap in knowledge and reflection in the literature and clinical studies of self-management technologies for paediatric patients, particularly in relation to how mHealth-enabled illness monitoring promotes and resonates (or otherwise) with minors' learning and illness management.

As Beacham and Deatrick (2015) argue, minors take the first steps of takeover of responsibility for illness management at very young ages. In elaboration of this I show in Article One how such a takeover of responsibility also implies adjusting the management to their current lived realities. As offering an alternative image to the 'data-proficient self-manager' in the projects, I found with the minors to a large extent that they had material and bodily trial and error approaches to learning illness management. Such adjustment or 'tinkering' with illness management objects and scripts is less explored in social studies of illness management. As shown in Article One, minors *do* have a remarkable capability to adopt objects and technologies that are not designed for them, and tinker with them to fit their own priorities and settings. As STS scholars have shown with adults (Langstrup, 2013; van Hout, Pols and Willems, 2015; Mol and Law, 2017; McDougall et al., 2018), minors have unconventional practices of managing, learning, negotiating, reorganising, and experimenting with prescribed procedures and treatment equipment in the socio-material settings that constitute their everyday lives. Thereby the minors are 'becoming', yet this is a becoming that is driven by their current way of being. Minors, like adult patients, try to find solutions to live with their illness, as argued by Pols (2013) .

My troubling of ‘self-management’ apps for minors furthermore gives rise to new perspectives on the mixed evidence of mHealth technologies’ usefulness with minors. Maybe minors that use an mHealth app cannot recognise themselves in the data-proficient self-managing patient-representations that the app assumes. This might lead to minors’ rejection of the app or to a lack of learning outcomes. If mHealth emphasises illness management as learning by data it misses reflecting upon the *journey* of minors to becoming able to convert health-related data into practices of illness management. Also, if an app directs a data-literate adult way of handling illness, minors might find it hard to align such kinds of illness management with their own physical experimentation. A conflict between the two illness management ‘regimes’ might cause the minors to limit engagement with the illness management regime of the mHealth app – or their own. Thus, if mHealth technologies reflect what the minor *ought to be* able to do as an adult individual, I see a risk that minors will limit their own creative processes of learning, or they might feel incapable because they cannot live up to these representations and they may lose courage. On the other hand, minors (and parents) might *not* feel pressure to obtain ‘the adult ways’, of producing, interpreting, and acting according to data, but rather see it as something that can also be experimented with. Indeed, I did witness how parents allowed their children to interact with ‘adult’ injection devices and expensive treatments in both treatment situations and play. The parents for the most part *do* encourage and support minors’ learning and alternative engagements with illness management.

Promoting illness ‘self’-management as an individual effort

Third and finally, attending merely to the minor (or parent) as the individual determinant for how illness management is conducted disregards the many other *things* that play a part in this – illness management is an inherently socio-material process.

As we see from the results in Article One, no one human actor determines how illness management plays out. For instance, the common establishment and editing of a home treatment script for where, how, when, and with what objects treatment is carried out, seems crucial for a satisfactory completion of the procedure of treatment management. The minors’ contentment with home treatment seems to depend on being involved and involving their own objects, timeframes, and sayings in the editing of the script and experiencing what works best. However, the mHealth projects of my study assumed that the users would take an individualistic role. Trnka (2016) similarly shows that health apps for young people disregard the importance of inter-sociality of care (to receive and give care to others) by posing an individualistic approach to the users. Slater et al. (2017) argues that notions of self-management activities in mHealth needs to be shaped in accordance with the physiological and psychological maturation processes of minors. In extension of this, I find that this shaping should possibly also imply an attuning of the proposed 'self'-management practices of the socio-material assemblages that make possible minors' engagement. This implies increased attention to the caretakers' role in mHealth-proposed illness management setups (Ellis *et al.*, 2007; Vinther, 2020) but also, as I argue, the involvement of various materials in the script-making of illness management.

We should therefore take an interest in how things and people interact in certain situations of managing the illness. As other STS scholars have argued (Mol, Moser and Pols, 2010; Danholt and Langstrup, 2012), privileging the attention to people with regards to self-management of illness risks disregarding materials that also influence such practices. This also applies to illness management with minors.

To summarise the three points above, the purposing of mHealth in terms of increasing practices of self-management, and the similar concepts of responsibility, autonomy, self-empowerment, and health data, seem to reflect the perspectives of adult patients and adult caregivers. These adult-focused approaches may come into conflict with the collaborative, experimental, and creative ways in which minors engage and learn about how to manage illness in accordance with their concerns for other aspects of themselves and their lives. Adults' responsibility for minimising risk for children is naturally important, however, resistance towards allowing minors to experimentally engage with technologies and their own health issues removes opportunities for minors to gain experience – to learn by mistakes (Christensen and Mikkelsen, 2008). That said, because parents and domestic orchestration play a part in how the illness is managed, technologies can be tinkered with and become part of the domestic management script if caretakers find them essential for the well-being of the minor. This would also count for mHealth technologies even if less attuned to minors' assemblages of care and management, while still providing functionalities that are regarded as important by caregivers and healthcare providers.

Troubling the user- and data-driven design approaches in mHealth innovation

Minors are being involved in the design of mHealth technologies. However, I here trouble the ways in which user-driven methods are orchestrated and how minors are represented as users in the design processes. I pose three points of concern about how the configured user reflects minors' lived realities throughout the mHealth design processes.

Momentary involvements in design

First, the mHealth projects strived initially to involve minors in the design process. As Druin (2002) and Meyers et al. (2007) have argued there is an increase in attention to offering minors an engaging role in technological design rather than placing them as mere consumers. Yet, like Shin and Holtz (2020), I found that actual involvement of minors in the design processes were limited to just one or a few activities.

Like the feminist STS scholars' that show how male developers can come to bias design towards males (Oudshoorn, Rommes and Stienstra, 2004), I remark that the project members were adults that made use of design methods more attuned to adult patients, and that better converted insights from adult patient user groups to further the design. I argue that the limited involvement of minors fuelled the process of biasing the design against the minor user and towards the adult user. As we show in Article Two, the mHealth projects minimised involvement of minors to momentary activities in the beginning and user tests of prototyped designs. Furthermore, the projects minimised conveying the insights gained with minors to other phases of the design process. I interpret this to mean that if there are less 'target group check-ins' to feed back into the emerging design, the design might evolve into something that does not fit this target group. The configured user could subtly change shape without it really being noticed by project members. The terms 'user-driven' might in this perspective be seen as misleading, regarding the lack of continuous involvement of physical representatives of the minor target group. This brings me to my second point.

Data representations of users

'User-driven' can be understood as a design process driven by different kinds of figurative or imaginable representations of the target group. I here argue how such a user-driven design approach can bias the design against minors. The figurative representation of users in the design process implies collecting different kinds of information about the targeted group of people and using this to drive the design (Sleeswijk Visser, van der Lugt and Stappers, 2007). User-driven design can thus be carried out without having real target users involved in every step of the process. In this case, the design methodology rather implies that the developers pay attention to the information they have on the targeted group and drive the design accordingly. The attuning of the design to the target group thus depends on how well the accumulated information represents the target group and how well developers consult the material and script the design accordingly. If the information retrieved is in fact not representing the minor target groups, then the design process is driven away from this target group.

This suggests that although data-driven design *can* be a kind of user-driven design method one has to be sure that cumulative data generations in fact keep representing the variety of target groups that one wants to direct the design towards. In the article we show that minors are particularly difficult to maintain throughout the design process because they constitute a small population in contrast to other groups, and the datafied information about them is limited. We show that there were challenges in the projects in accounting for those groups that are not used to dealing with data, that are not represented by data, and that are restricted in their access to data infrastructures. Other scholars have pointed out that most mHealth interventions fail to be integrated into the lived realities of adolescents (Majeed-Ariss *et al.*, 2015; Ossebaard and van Gemert-Pijnen, 2016) and that we know too little about the development of mHealth for minors to provide insight into how the technologies relate to minors' real world settings. (Majeed-Ariss *et al.*, 2015). While scholars have called for identifying the structures that restrict and enable minors in their lives (Alanen and Mayall, 2002), our findings suggest that attention should furthermore be given to the structures that restrict and enable *their representation* in design processes, especially in data-driven design processes. Specifically we show in Article two that economic, legal, methodological, and structural purposes move the representations of the user away from representing minors. I argue that my attention to the troubles in driving mHealth design by datafied population provides new perspectives on those cases where mHealth fails to obtain usage with minors. Data-driven mHealth design processes might not be alerted to ensuring that they actually represent the minor users in the dataset that they are using. If the user-configurations are driven by data representations of other groups then the app being designed could possibly be mistuned to characteristics of the minor user. As Brady et al. (2015) argue, minors' agency is enabled and restrained in specific situations of power and participation. This, I claim, also goes for their possibilities of being represented by user-representations in mHealth design processes.

Reliance on target-users' abilities to convey insight

Third, I argue that attention to 'the user' in mHealth projects possibly reduces the projects' insights into the situated socio-materiality of minors' illness management. This point is related to the one I posed earlier about 'self'-management and minors: I again focus on the contradiction between mHealth innovations' attention to the individual and minors' particular embedment in socio-material settings. Yet, I now focus on the *design methods* and how these (dis-)enable insight into particular collaborative processes of managing illness.

Klingensmith et al. (2005) and Shin and Holtz (2019) call for attention to digital health innovations' lack of recognition of minors' everyday life schedules, which results in such technologies' lack of alignment with these schedules. Similarly, I found that the mHealth projects lacked insight into minors' practices of illness management. I interpret that such knowledge is lost in the projects due to design methods of 'the user'. Because attention is to the user as an individual and what this kind of person thinks, needs, and wishes, the design methods can be limited to invitations for participation in workshops, focus groups, interviews, and user tests. Whilst such activities can bring about important insights, they may well miss the fuller picture. The invited target user participants are not in their everyday lived reality when they are asked to convey their experiences of living with illness. They are dislocated from the various socio-material situations where their illness and lives are otherwise happening. Furthermore, people's input into the design process relies on their ability to articulate insight into their daily processes of organising practical, structural, situational, and perceptual experiences of illness, and minors are hardly able to do this. The argument I am making, and that other scholars have similarly made (de Moor *et al.*, 2010) is that if we wish to know the ways in which targeted users live, organise their lives, make use of objects and technologies, experience bodily sensations, relate to others, and establish practices such as illness management, then simply getting their verbal inputs might not be enough. Just because minors participate in design and voice their needs and wishes this does not necessarily result in designs that they can or will use (Smith *et al.*, 2014). Instead, mHealth design requires *innovators to participate* in the targeted group's lived realities and seek knowledge about underlying structures of illness management. This would apply to mHealth projects targeting adult users as well, however it applies particularly to those that target minors, given minors' boundness to caregivers' more subtle orchestration of their everyday life that minors might have little chance of recognising, and thus voicing, in an mHealth project.

The techno-anthropological multi-sited approach behind this study enabled my own 'participatory engagement' (Wong *et al.*, 2015) and 'hybrid sensitivity' (Botin, 2013) to both what minor's lived reality with chronic illness is and what drives the design processes of mHealth. Looking across these sites, letting aspects of the one direct attention to the other, helped with exploring dichotomies (Marcus, 1995) between the projects and the minors, concerning illness and management across the sites. This suggests a more productive methodology than the user-driven approach taken by many mHealth projects, as it enables explorations of the particular circumstances that orchestrate minors' lives and lets them inform the design processes. I elaborate on this in a 'contribution' paragraph below.

Troubling the patient-centric paradigm of mHealth innovation

A turn against paternalistic pathological approaches to healthcare has inspired a healthcare paradigm that recognises the interconnection between illness and life as it is lived and experienced by people (Sullivan, 2003). mHealth is part of this new paradigm, with its focus on monitoring patients' everyday life experiences of illness. This makes sense in order to enable directing care not only at bodies, but to the person and their well-being in general. However, I here trouble some aspects of inscribing this paradigm into mHealth technologies for minors. I reason that in trying to fix the troubles of paternalistic, pathological, and impersonal healthcare, the emphasis on patients' experiences and 'living with' illness give rise to other troubles with or for minors.

Measuring illness experiences

First, my focus group discussions with minors, parents, and young people suggest that besides *monitoring* of how illness affects their lives, such notions of illness' hampering of everyday life aspects might be *amplified*. I here argue for mHealth innovations' more thorough consideration of how various kinds of measures in mHealth make sense with minors.

I found that minors live ambivalently with illness; they generally strive to see themselves as normal, while, on the other hand, they know that they are 'different' because they suffer from an illness. They are ill but this does not/should not always matter. They *are* interested in their own illness and management of it, but this interest does not belong in all situations of their lives. Other scholars have similarly identified how adolescents attempt to diminish association with their illness, focus on positive issues of their lives, and avoid rumination on the illness, to enable a balance between their illness and their broader self-concept (Woodgate, 1998; Garnefski *et al.*, 2009). Freeman and Neff (2021) look at health self-tracking app practices of young people (aged 16-18) and find that affordances of health apps are different in different spaces and depend on the context of the individual user. I furthermore found that parents and the youth panel anticipated that monitoring of various kinds of illness experiences could possibly influence how such illness experiences are shaped. Parents and the youth panel were reluctant to seek out *how* intertwined the illness is with everyday life, because this would possibly increase how ill the minors felt generally. When the app draws attention to how a broad range of aspects of life is possibly related to illness, this could cause minors to experience these life aspects in the light of illness when they did not before. Mol (2000), Lehoux (2008), Veerbek (2005), and Hofmann and Svenaeus (2018), have argued that technologies designed to generate insight into people's health also shape these peoples' relationship with, feelings about, and perceptions of the very same matter. Similarly in my case, technologies designed to generate insight into minors' *illness experiences* were anticipated by minors, parents, and young people as being able to shape such illness experiences.

The insight into how a minor's illness limits their daily life, how their daily life activities influence their health state, and how treatment and experiences of symptoms connect, might serve as valuable knowledge for educating them, and lead healthcare providers to adjust treatment to better correspond with the life they are living. However, I interpret that the activity of frequent monitoring of, and thereby attention to, these interconnections by aid of mHealth, can cause them to see the greater whole of their life from the angle of illness. Similarly, Vinther (2020) showed that minors living with JIA that used an mHealth app experienced their illness more in situations where they did not otherwise attend to their illness. On the other hand, parents, minors, and young people in my study (Article Three) anticipated that a few specific monitoring measures could increase their learning about the more practical or biomedical aspect of their condition, namely symptoms, treatment, and particular activities that they perceived triggered their symptoms. Likewise, Vinther found that minor JIA patients perceived some monitoring as being helpful to control and understand their symptoms and limit their anxiety around symptoms (ibid). Thus, monitoring of illness experiences *does* change illness experiences with the patients, for better or worse from minors' perspectives. Monitoring can be good in supporting minors' learning and their ability to manage, for instance, treatment, accordingly with symptoms and activities that they *do* accept as interrelated with illness. Yet, it can also be bad in the sense that it can hamper minors' abilities to disregard illness in certain situations because the monitoring encourages attention to aspects that minors otherwise do not link to illness. This, I argue, calls for a nuanced differentiation between and reflection about the consequences of the *kinds* of measures that mHealth apps enable. This leads to my next point.

Underlying imaginations in mHealth of the achievement of normality for patients

Second, I trouble what I find to be an underlying assumption in the field of mHealth; that seeking out how illness correlates with one's everyday life activities, capabilities, emotions, and feelings leads to increased health and normality. In the mHealth projects that I followed, there was never an attention to how a prompting of users to seek insight into the interrelations between illness and daily life resonated with minors' ways of perceiving illness. No debates revolved around the perceptual processes that an mHealth-enabled search for correlations between everyday life and illness would inflict on the minors and their values of normality. Rather, the underlying assumption in the JIA project was that, by helping the young people to see how their everyday life was influencing and was influenced by their illness, they would be 'empowered' to act on it, achieve a better management of the condition, a better health state, and following this, increase their sense of normality.

'Normality' was thus seen by the projects in light of control of the condition, rather than in terms of minors' perceptual relationship with their illness and their lives in general. However, my findings with minors, parents, and young people suggest that a sense of normality is not only strived for through adequate illness management and optimal treatment. A state of normality is almost impossible to reach with the minors of my study because the illness is chronic and might fluctuate. Also, even optimal control does not necessarily mean that the illness goes unnoticed; there might still be symptoms and the recurring treatment and control raises awareness of the condition as well. Furthermore, there are opposing concerns between managing illness and living a normal life, and sometimes concern for one excludes concern for the other. Lastly, a sense of daily normality is needed by minors and is not something that can depend on reaching an optimal health state. My findings in Articles One and Three, and those of other scholars (Brady, Lowe and Olin Lauritzen, 2015; Lambert and Keogh, 2015), show that normality is linked to abilities to take part in social encounters rather than considered in terms of health. The critical call for further exploration that I am making is to an inbuilt assumption about normality in some mHealth apps. The assumption would be that normality *can* be achieved through exhaustive investigation of correlations between symptoms, triggers, treatment, and activities. It might not be so, and the demanding engagements of minors to seek this out might in themselves hamper their sense of normality, as argued previously.

The measurements of patient reported illness experiences that are implemented in various mHealth solutions vary greatly, and range from 'objective' to 'subjective' (Bruce *et al.*, 2020). I interpret that my findings, along with those of Vinther (2020), point to the more 'objective' measures of treatment and the characteristic symptoms and triggers being those that make most sense to parents, minors, and young people. This is because these can be directly used to inform what these groups see as illness management and possibly help in decreasing the attention to illness because a greater sense of control seems to be enabled. On the contrary, the more ‘subjective’ measurements of how one feels about the illness, and those that focus on illness inflicted limitations and hardship that is beyond an obvious course of action, possibly increase the negative experiences of illness. Not all kinds of patient experience measures of life with chronic illness might make sense to all kinds of diagnosis, possibilities of treatment, kinds of people, norms of living, and situations of everyday life. The measuring of some illness experiences might make sense to some families because these reflect what parents and minors themselves connect to the illness and what they regard as possible to improve. However, it might not be beneficial to extensively seek out a broad set of aspects in which the illness affects their lives. I therefore trouble that mHealth apps present a ‘list’ of many daily aspects in which the illness might hamper minors’ daily lives. This is because such a list might be difficult for minors to integrate with their more selective approach to illness, which could lead to their rejection of the mHealth app. The value of keeping some aspects of life normal thus might provide hypotheses for why some mHealth technologies show difficulty in sustaining their use by minors. This leads me to my last point.

Applying a ‘living with’ approach to minors

Third, I direct attention to how a ‘living with’ approach might contrast minors’ more ‘ambivalent living’.

While minors are being asked to take care of their illness they are also being asked to live normally in some situations of their lives. To an extent, parents, minors, and young people living with chronic illness know of this discrepancy between being ill but also being ‘just like other children’, as I show in Article Three. They know that they will never be ‘normal’, and that illness and management will always play a part in their lives, and they try to accept this. Their ways of organising their lives into spaces where illness is given attention and spaces where it is not, can possibly be seen as a way of accommodating the requests to both take their illness seriously and to be normal – a balancing act. As Wind (2009) expresses it, chronicity is somewhat to live between the categories of normal and sick. Minors’ settlement in this ‘betweenness’ seems to demand a flexibility to shift between attention to the illness and to their normality. I suggest that this is not reflected in the application of the ‘living with’ paradigm to minors that live with chronic illness. According to the findings of

Vinther's study and mine, an integrative approach to illness and life seems to heighten the experience of illness for minors, which seems a counter-productive effect in terms of the contemporary non-pathologising paradigm. What I am arguing here is that we should be more attentive to how ideas about illness as an integral part of living are transferred to minors.

Jiang and Cameron (2020) showed how research until now has ignored accounting for the impact that mHealth technologies might have on patients' perceptions and experiences with illness in relation to particular contexts of the patients. Though my study did not look at technologies in use, my findings suggest that there could be a discrepancy between mHealth technologies that indicate a 'patient-centred'-discourse, or as other scholars have termed it; an 'anytime-anywhere' discourse (vanden Abeele, de Wolf and Ling, 2018) of illness, and minors' more selective and situational perceptions of how illness and life interrelate. As argued by Harries, Rettie, and Gabe (2019), adolescents living with chronic illness need to establish ways of living that balance the concerns and norms of some particular social situations, for instance interaction with peers, against demands of illness management technologies. I interpret a conflict between this norm of presenting oneself as normal and mHealth imposed attention to illness as being interrelated with everyday life. Against this background I, like others (Frøisland, Årsand and Skårderud, 2012; Rhee *et al.*, 2014; Fedele *et al.*, 2017), challenge the assumption that mHealth is particularly suited for minors, with its orientation towards information about the illness anywhere and anytime, instead of more scheduled consultations and evaluations of the illness.

To relate this to the mixed evidence on mHealth with minors, a systematic review of Stinson at al. (2009) showed on the one hand early evidence for improving the management of symptoms, and on the other a lack of evidence for improving minors' knowledge about the illness and their quality of life with these technologies. Thus, while the purpose of mHealth is to improve quality of life along with improving control of treatment and symptoms, these areas of minors' lives might be far more complexly interrelated than imagined. While it might not be that improved control of the disease necessarily increases general well-being, and vice versa, my study helps in nuancing perspectives on the matter. My study points to well-being of the minors also having to do with their abilities to 'ignore' illness in some situations, while engaging in a more practical engagement with illness in other situations. Improvement of treatment and symptoms might not alone heighten quality of life. My findings in Article Three point out that increased attention to illness might in fact negatively affect some experiences of life with minors. The time-spaces for and the ways to dedicate attention to illness management, seem to be important for the general well-being of minors.

To summarise these three paragraphs, no particular discourse of how minors perceive illness in relation to life and normality seem to be found in the field of mHealth with minors. Instead, an 'all the time and anywhere' approach to illness seems to be reflected in many mHealth technologies for minors, given their encouragements of minors to monitor a broad variety of their illness experiences in relation to their everyday living. I propose that this leaves little room for the more selective and situational way of seeing a chronic illness in relation to everyday life that I identify with minors. Though there is naturally a need for caring about how minors live best with their chronic illness, I find that there is reason to trouble the notion of 'living with' illness as an approach to healthcare with minors. This is because I see that, being able to identify as normal, at least sometimes, is particularly important to them. I therefore call for questioning the patient-centred/whole life/living with/anytime-anywhere discourse in illness approaches to minors, and for further exploration of their own complex and contradictory perceptions of themselves as both ill and normal, in mHealth innovation. I call for more exploration about *which ways* of 'increasing' attention to illness make sense with minors, to allow for the 'limiting' of illness in minors' lives.

Marginalisation of minors in mHealth innovation

Here I summarise the discussion points above as an answer to my initial research question: *How does the creation of mHealth technologies relate to particular circumstances of children and young people and their everyday life with chronic illness?*

mHealth technologies are scripted with certain assumptions about who they are for and how they should be used. These assumptions to a large extent draw attention to the patient's self-sufficiency in managing their illness, their compatibility with health data practices, and their willingness to engage with illness' interdependency with everyday living. Such a preoccupation with patients' 'self' in managing their condition seems to be strongly embedded in the designing of and purposing of mHealth for a generalised adult patient population. Preoccupation with individuality and self-sufficiency also seems to become an outcome of the mHealth projects that target minors that live with chronic illness. This means that mHealth projects targeting minors can come to rely on adult patient defaults, purposing mHealth to increase patients' self-management and abilities to partake in data processes of health. From a recent historical perspective of health interventions and health technologies, minors have been subjects of 'repurposed technologies' and of fitting minors into models built on adults (Freeman and Neff, 2021). The reliance on such adult patient defaults for purposing and designing mHealth with minors leaves out opportunities for discovering and attuning digitally enabled illness management tools to minors' particular ways of living with chronic illness. With minors that live with chronic illness, there are some crucial circumstances to consider in relation to the purposing and design of the technologies. These circumstances include (but are not limited to) minors' particular embedment in socio-material assemblages of care, restrained association with data-driven healthcare work, and situational perceptions of illness. Yet, the circumstances are overlooked or become barriers in the adult-default innovation process. In the aspect of attuning mHealth technologies to minors' particular ways of managing illness and participating in driving mHealth design to resonate with their lived realities, and balance between normality and illness, mHealth innovation seem to be struggling. Due to strong forces in the field of mHealth innovation that drive innovation towards the needs of/for a self-managing, individualised, and datafiable majority population, minors seem to constitute a marginalised group in the field of mHealth.

Contributions to knowledge

This thesis has proposed reviewing mHealth's relevance with minors in a new light. Whereas clinical studies and literature reviews have drawn attention to the mixed evidence of the use and outcomes of mHealth for minors I have strived to explore and trouble the attuning of mHealth innovation to minors' lived realities with chronic illness. I have enabled a thinking from marginalised points of view, in order to generate knowledge (Harding, 2004; Hartsock, 2021). The relationship between mHealth and minors that live with chronic illness is not exactly troubled in the sense that health informatics literature and political references to mHealth merely witnesses that mHealth with minors is challenging. Unfolding and explaining the challenges rather seems to go unexplored. Yet, this thesis makes a fuss about the inability of mHealth innovations to attune to minors. This thesis troubles it.

In the following I reflect on how the study contributes to knowledge about minors that live with chronic illness, to the field of STS and feminist STS of digital health and minors, to methodologies for studying digital health technologies in the making, and lastly to reflections on 'minors' voice' in the innovation field of mHealth. By these contributions I hope to enable a stirring up of contemporary self-management approaches, user-driven design methods, and patient-centred visions in mHealth innovation that are concerned with minors' lived realities with chronic illness.

Contribution to knowledge on minors living with chronic illness

My study contributes to knowledge on how minors engage actively in their illness management and enable their own learning about their illness, management, and their own evolving role towards it. The main contribution lies in my increase in attention to how treatment equipment and everyday objects are arranged by the minor to facilitate their active involvement. Furthermore, I point to how minors seem to need being involved in trial and error practices of the home treatment set-up, in order to accept a 'best practice'. I also unfold some nuances to the knowledge of how minors strive for normality (Lambert and Keogh, 2015), namely that this striving is situation-specific. My nuancing lies in exposing minors' ambivalence towards 'living with illness'. Minors value being able to shift between attending to their own normality and situations where they can focus on learning about their illness and treatment. For the minors of my study in Denmark a demand for their normality is related to applicable norms among minor peers to not draw too much attention to oneself as standing out and craving the concern of others.

Contribution to a critical STS field on minors and digital health technologies

Minors and their particular socio-material realities have received little attention in STS, with a few exceptions e.g. Ruckenstein's (2010) work on minors and virtual toys, and less so regarding digital health technologies and chronic illness. Those that I did encounter were Vinther (2020), Trnka (2016), and Freeman and Neff (2021). My main contribution to STS is to highlight minors as enabled and restrained agents in illness management, in data-driven design processes, and in healthcare paradigms and interventions. Furthermore, I contribute to the field of feminist STS by offering new perspectives on how a group can be marginalised in technological innovation. *Troubled attuning* focusses on the abilities of technological design processes to recognise and resonate with the circumstances of a particular group of people. This group might be distinctively different from the groups that are usually associated with the specific field of technological design. By mobilising a criticality to mHealth design processes I articulate the subtle process of how a group of target users can be forgotten in data-driven design processes. I articulate bias and marginalisation in data-driven development.

Methodological contribution

van Hout, Pols and Willems (2015, p. 1206) state that it is not clear how telecare changes practices of care and quality of care, because it is seldom documented 'what the situation was before telecare is introduced [which is an] obstacle to learning about the workings of the new technology'. This also means that the technology is assessed not in relation to real needs but instead the technology makes suggestions about what the problem is and how it should be solved (Pols, 2012). In a sense, I now, at the end of my study, face the opposite challenge; I know what the situations of minors' lives with illness are before an mHealth technology is introduced, however, I cannot foresee how practices of illness management with minors will change when/if mHealth is introduced. Yet, I have been able to trouble the ways in which mHealth innovation is knowing and not knowing about minors' lived realities with chronic illness, and I have witnessed why this knowledge is itself difficult to achieve. My double-sited ethnographic methodology, of commuting back and forth between minors' lived realities and mHealth innovation's design processes and purposing, has enabled atypical explorations in both sites. Attention to minors' particular practices, positions, and perceptions helps trouble the increasingly individualised self-care and self-management, the data-driven innovation processes, and the patient-centred mHealth innovation paradigm. With my constant attention to how particular circumstances with minors both fits and does not fit the configured user I enable exploration of how data became a driving force in the mHealth projects that were otherwise apparently 'user-driven'. The other way around, the attention to mHealth-enabled self-management and patient-centred perspectives, helped in bringing forth minors' particular ways of practicing and perceiving chronic illness during fieldwork and analysis. The particularities that this exposed were especially the tight connections to materialities and various situations that play key roles in how minors live with (and without) illness. The double-sited ethnographic methodology took inspiration from situational analysis and insisted on placing the researcher as the participant in different situations. The methodological approach was very useful for analysing technologies in the making and in the attuning to a specific group of target users.

Closing reflections on 'minors' voice' in mHealth innovation

I have throughout this thesis articulated my reluctance towards 'giving voice to children', towards child-centred approaches, towards seeing minors as participants in my study, and towards calling for furthering minors' participation in mHealth design. The reason for this is my growing attention throughout this study to how this can be problematic in different ways. First, claiming to centre attention around a specific group, or being driven by a specific group, can be a somewhat hollow promise. It is difficult to argue whether a research process or design process centres around a particular group or not. In line with White (1996) and Rogers' (2003) arguments on participatory approaches, the 'centring' of innovation, healthcare, or research around a group of people can be used to fulfil strategic purposes rather than fit the actual needs, values, and experiences of this group. There is the temptation to select between the issues that can be ascribed to the group. Furthermore, saying that something is developed through central orientation to a particular group can be used as a strategy to convince this group to follow agendas that actually serve other hidden top-down agendas (White, 1996; Rogers, 2003), such as getting patients to increase their own illness management. Second, and more importantly for my reluctance to aim at 'voicing minors', is that centring attention to some-*one* risks overlooking the particular circumstantial and situation-specific settings that they are interrelated with. In this study I have wished to enable knowledge about minors' realities of living with illness, and their chance of receiving mHealth technologies that are attuned to them, make sense to them, and help them manage illness. By the readings of contributions from techno-anthropology, STS, and feminist STS I have been made very aware not to prioritise an essentialist approach to people that overshadows attention to the situations, structures, norms, values, things, and other people that along *with* the people constitute the matters of interest. Stated bluntly I have attempted to not only listen to the minors, but to listen to the situations they find themselves in in everyday life with illness, and in design processes. What I find that I convey in this thesis is thus not voices of minors – it is insight into minors' particular circumstances of living with illness. As a last note on this, I see pitfalls in making a call for increasing the participation of minors' in mHealth design processes. If I should make a call for an mHealth innovation field, it should be for troubling the way in which attention is directed towards minors in light of their becoming, their individuality in illness management, and their abilities to voice their complex lived realities in design processes. Rather than increasing the participation of minors in mHealth projects I encourage projects to participate in minors lived realities. By applying a thinking of and methods for attuning the design to minors it is rather the orchestration of people and things around the management of illness that is of attention rather than merely individuals. More specifically, I encourage making use of ethnographic methods in various situations of minors' lives with chronic illness. Furthermore, I encourage awareness of inbuilt adult defaults in the process of mHealth design. This includes attention to the ways in which knowledge is gained about the collaborative, material, and situation-specific ways that illness management and learning are achieved, and the specific ways in which minors relate to and are represented by health data. In extension of this I here lastly propose some reflection points for the field of mHealth innovation to engage with in troubling mHealth's attuning to minors:

- What are minors' relationships with illness and normality, and in what situations?
- What is illness management with minors and with who, what, why, when, and how is it happening?
- How do minors relate to health data, find use of data, have access to data, and how are minors represented in datasets that drive technological innovation?
- What kind of terms should be used for the purpose of supporting illness management so that it specifically reflects the current ways that minors are engaging with their illness and treatment? Should it be digitally enabled 'healthcare' rather than 'self-care'? 'Condition management' rather than 'self-management'? 'Practicing' rather than 'empowering'?
- Could an mHealth design project take an 'opposite-participatory' approach, so that the project's members and prototypes strive to participate in the minors' lived reality during the design process?

Conclusion

This study aimed to explore how mHealth technologies are attuned to minors that live with chronic illness, in consideration of what characterises their lived realities. Based on qualitative analysis across minors' lived realities and mHealth design projects, I conclude that there can be considerable discrepancies between the ways in which minors live with chronic illness and how mHealth innovation purposes and produces technological designs for this group.

Stated in basic terms, the study pointed to three overall suggestions for why it is challenging to develop mHealth apps that resonates with the needs and realities of minors that live with chronic illness. First, while mHealth innovation focusses on idealised autonomous abilities of the patient to manage their illness, minors' engagements with their illness and treatment is much more collaborative, experimental, and situation specific. Second, while mHealth design processes focus on health data they miss opportunities to involve in the design minors' less data-oriented perspectives on what a supportive illness management system would entail. Third, while mHealth to a large extent purposes to recognise illness as an integral part of the lives of chronically ill patients, it might come into conflict with minors' priorities of some parts of their lives being about normality instead of illness.

The results thus indicate that mHealth designs can be biased against minors, because the design processes rely on patient ideals, design methods, and purposing that originate from approaches to an adult patient population. The results further indicate that the establishment of design approaches that enable opportunities for recognising and attuning the technological design to minors' lived realities are limited, given driving forces in the field of mHealth innovation that encourage the adult defaults in mHealth design.

My research illustrates how mHealth innovation that is preoccupied with patients' *becoming* illness self-managers hardly resonates with minors' present *being* of practicing and balancing illness management in their lives. This research also raises the question of what would characterise an mHealth design methodology that *does* enable the production of a design that resonates with minors' particular circumstances of living with a chronic illness, and that minors could use. Future studies on the ways in which a broader variety of illness approaches, design methodologies, functionalities, and healthcare purposes in mHealth projects return diverse resonances with minors' lived realities, might enrich my conclusions. Furthermore, the area of mHealth innovation is diverse. A nuanced terminology for the varieties of technologies that this field encompasses, in terms of for instance functionality, approach, purpose, and role in illness management, would enhance the generating of insight into what kinds of technologies resonate with minors' particular circumstances of life with chronic illness.

I began this thesis with wondering how mHealth technologies are designed and purposed for minors, in light of the mixed evidence in the area. Throughout the first part of my study, I learned how minors' ways of living with chronic illness are situational, ambivalent, material, and collaborative. This drew my attention to mHealth projects' actual opportunities for considering and working with such insights in their shaping of technologies for managing illness. I became interested in the driving forces that blocked the explorations of minors' lived realities in the projects. I *troubled* the driving forces of purposing and practicing mHealth design, in light of how they drew attention away from the minors' particular circumstances. I troubled how mHealth innovation assumes minors as becoming adults, presupposes how patients relate to data, and induces engagements with chronicity as an inseparable part of living.

This thesis is the minority report of the troubles that I saw characterised attuning of mHealth to minors. It is the report that unfolds what the contradictory outputs of mHealth for minors might hint at. It is the report of what might inflict marginalisation of a minority group in a socio-technical innovation system.

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Appendix

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ELSEVIER

The socio-material self-care practices of children living with hemophilia or juvenile idiopathic arthritis in Denmark

C.M. Bagge-Petersen*, M. Skovdal, H. Langstrup

Department of Public Health, University of Copenhagen, Øster Farimagsgade 5, Postboks 2099, 1014, Copenhagen K, Denmark

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ABSTRACT

Growing up with a chronic disease can take its toll on children and their families, and if poorly managed, be disruptive to children's long-term health and wellbeing. While parents and health service providers do play a central role in disease management, children's own self-care practices often go unnoticed. In existing literature, children's self-care practices only tend to emerge in research with adolescents who “transition” from pediatric to adult clinical care services. This study was conducted in December 2017 to May 2018 and explores ethnographically the self-care practices of children affected by hemophilia or juvenile idiopathic arthritis in Denmark, with a particular interest in how social relations and material context affect their pre-transition self-care practices. A total number of 16 children and adolescents aged 7–17 years and 39 family members participated in the study. We find that the children participate in three socio-material self-care practices. Firstly, the children actively engage in home treatment of their bodies by changing the setup of medical equipment and incorporating everyday materialities to make treatment more comfortable. Secondly, they play games imitating their own treatment, using medical equipment on dolls or teddy bears to seek out experience and learning. Thirdly, they seek a sense of normality by tactically hiding material signifiers of their disease in online and offline encounters with peers. Our findings suggest that children living with a chronic disease establish and participate in a range of different self-care practices, and actively mobilize people and things around them to achieve precisely this. We conclude that these socio-material self-care practices are central to helping children make sense of living with chronic disease, both to maintain health and wellbeing, but also to gain greater independence. We encourage others to recognize children's pre-transition self-care practices, and the implications of these agentic capabilities.

Corresponding author. Øster Farimagsgade 5, Postboks 2099, 1014, Copenhagen K, Denmark. E-mail address: clba@sund.ku.dk (C.M. Bagge-Petersen).

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> Mathias and his siblings discuss when he was younger, terrified of the home treatment procedure for hemophilia. The siblings witnessed very unpleasant things, the mother adds; the parents had to force Mathias down while he screamed and cried. There was a phase when Mathias would sense it was time for injections and run off over the fields outside the house in his underwear. I ask him why he ran off. He tells me he had "needle anxiety", and that he ran away, but got scared when reaching the big road and had to return home.
>
> Field note on Mathias, 11 years old, hemophilia

1 Introduction

The field note on Mathias, a boy with severe hemophilia, exemplifies the strange, painful and frightening treatment procedures and feelings of loss of control experienced by many children and young people growing up with a chronic disease (Kazak et al., 2006). Being subjected to frequent procedures of home treatment is not easy, yet it is part of daily life for many chronically ill children around the world, like Mathias. Growing up with a chronic somatic disease has been associated with numerous challenges relating to children's medical adherence and compliance (McGrady and Hommel, 2013), parental influence (Cousino and Hazen, 2013), school attendance (Lum et al., 2017), and stress and coping (Boekaerts and Roder, 1999). Children with chronic diseases have also expressed having low quality peer relations (Lum et al., 2017) and doubts about disclosure of the condition to social relations (Fergie, 2015); experiencing victimization and bullying (Pinquart, 2017);

as well as challenges to sense of self, normality and acceptance (Hanghøj and Boisen, 2014; Venning et al., 2008). These challenges can have long-term consequences, with chronically ill children being at elevated risk of experiencing low health-related quality of life, anxiety, and depression (Verhoof et al., 2013). Whilst medical sociology and anthropology are expanding their studies of children's lives (Prout and James, 2015) and much has been written about the detrimental impact on children of growing up with a chronic disease, we know surprisingly little about how children participate in socio-material self-care practices related to their disease. Yet, such insight is critical to circumventing the detrimental impact of growing up with a chronic disease. Calls have been made for research examining how children develop independence (Pinquart, 2017) and capacity to deal with their disease, while maintaining adherence to medical therapy (D'Alberton et al., 2012). Such calls draw attention to children's relation with various treatment devices, their bodies and skills in what is known as the clinical "transition phase" of taking on practices and responsibility for their own care when moving from pediatric to adult healthcare services at around the age of 16–18 (Crowley et al., 2011; Stinson et al., 2014) but often disregard how children born with a chronic disease themselves develop strategies to self-care.

Against this background, we set out to explore ethnographically the everyday self-care practices of children growing up with hemophilia and juvenile idiopathic arthritis (JIA) in Denmark in December 2017 to May 2018. Given the paucity of research providing a children's perspective on self-care practices, and inspired by similar research with adult patients, we developed a socio-material conceptual lens for exploring such practices. Research, particularly within Science and Technology Studies (STS) and Practice Theory, has shown how adult patients with chronic diseases manage self-care by creatively "tinkering" with prescribed procedures and treatment devices, adapting them to their individual social and material contexts (Langstrup, 2013; McDougall et al., 2018; van Hout et al., 2015). Moreover, self-care is from this perspective seen as always being a relational accomplishment, enabled by wider socio-material infrastructures of care. By applying this lens to children we find three core socio-material practices characterizing the children's agentic self-care-work enabling them to actively engage in, learn about and live with disease. One: the children actively engage in home treatment of their bodies by "editing the script of medical equipment" and by incorporating everyday materialities to make treatment more comfortable. Two: they play "imitation games" of treatment procedures, using treatment equipment on dolls or teddy bears to seek out experience and learning. Three: they normalize themselves among peers by tactically hiding or displaying material signifiers of their chronic disease in both online and offline encounters. Common to these three practices is that all are articulated by the children as crucial to their physical and mental wellbeing, and that the children are actively engaged in them. Thus, with the following ethnographic analysis we argue that children, like adult patients, practice socio-material self-care, however they do so in response to the struggles and care-aims specific to their own social, material, emotional, developmental and bodily realities. Our contribution lies in voicing children's agentic capacities in practices that concern their own wellbeing and everyday living with chronic disease.

1.1. Growing up with hemophilia and juvenile idiopathic arthritis

Although the exact numbers are unknown, hemophilia and JIA are estimated to affect approximately 200 and 1200 children in Denmark respectively (Bløderforeningen, 2019; Gigtforeningen, 2019). Hemophilia and JIA both make themselves present in the everyday lives of children, with symptoms, precautions, and home treatment procedures affecting their everyday life from the very beginning of their childhood. The diagnoses have been chosen as cases for this study of children's engagement in self-care because they both require families to be attentive to home treatment technologies, practical skills, symptoms, comfort and wellbeing of the child and not least integration of these factors into everyday family life. Further symptoms for JIA are fairly invisible (pain) but for hemophilia occasionally visible (bruises, plasters, port-a-cath) thus serving as cases of caring and living with visibility and invisibility of chronic disease. This constitutes a constant, complex and material framework of issues that needs to be cared for through various practices.

Hemophilia is a rare bleeding disorder most prevalent in boys, and caused by an inherited deficiency of a blood coagulation factor that leads to spontaneous and posttraumatic bleeds. If untreated, hemophilia can result in irreversible joint damages and lethal internal bleedings. The introduction of replacement therapy in the 1960s and the availability of prophylactic treatment reducing these risks, have much increased the possibility of patients with hemophilia living a “normal” life. Yet, despite major advances in treatment innovation over the past decades, children growing up with hemophilia today still need to endure frequent injections, hospital visits, and limitations in physical activities (Limperg et al., 2015). Echoing other child-focused chronic disease studies, studies of children with hemophilia highlight their difficulties in learning to self-treat (Paradi and Hilbig, 2014), and note how the disease can have negative effects on family life, peer relationships, and children's experiences of schooling, wellbeing and selfconfidence (Crawford et al., 2010).

Juvenile idiopathic arthritis (JIA) is a chronic childhood disease that causes inflamed, swollen and painful joints and reduces mobility. An estimated 30–50% of children with JIA carry the disease into adult life. The prognosis of the disease has improved drastically due to advances in medication, including the development of multiple biologic therapies. Nonetheless, disease-related complications and medication side-effects include eye inflammation, joint pain and inhibited growth. Research suggests that children with JIA experience poor health-related quality of life (Cartwright et al., 2015). This is evidenced by their hampered physiological, psychological, and social maturation (Venning et al., 2008), experiences of fatigue, and regular school absences (Nijhof et al., 2016).

Whereas this previous research has focused on challenges and the psychosocial impact of hemophilia and JIA for children and young people, little attention has been given to their practices of adapting to life with the disease (Cartwright et al., 2015), or to their competencies, perceptions and skills towards living with a chronic disease (Limperg et al., 2015) apart from interventional studies of transition and selftreatment (Crowley et al., 2011). Furthermore, we have limited insight into their own concerns and priorities in various situations of self-care, and how they themselves relate to and mobilize materialities and technologies when engaging with their disease.

1.2. Conceptual framework: socio-material self-care practices

While conscious of the many forms that disease self-management and self-care take, here we focus on the socio-material practices that help children actively support, learn about, and live with their chronic disease. Though the definition of, and relation between, self-care and self-management are not conclusive across literature on living with a chronic disease, self-care is often used in healthcare contexts to refer to the broader set of health-enabling behaviors that patients participate in to care for themselves. Disease self-management, however, often refers to more formally prescribed activities such as dosing and administering medication based on technology-supported self-monitoring (e.g. diabetics measuring blood glucose) (Lorig and Holman, 2003; Willems, 2000).

During recent decades, several studies drawing their inspiration from the field of STS, in particular the material semiotics of ActorNetwork Theory (Akrich and Latour, 1992; Prout, 1996) have unpacked how in practice self-care and disease self-management are interwoven and tightly related to the use of various technologies or material arrangements (Langstrup, 2013; Mol et al., 2010a; Pols and Willems, 2011). Technologies prescribed by health professionals for self-management might be the formal tools of care, enabling the delegation of tasks to the patient, which would otherwise be performed by health professionals – such as treatment kits for administering injections at home or digital technology for self-tracking. However, these tools do not in themselves ensure "self-care", but have to be domesticated in the context of everyday life (Laviolette and Hanson, 2007; Pols and Willems, 2011), "tinkered" with to fit into existing routines and material arrangements, and balanced in relation to other commitments and values that patients and their relatives have (Danholt and Langstrup, 2012; Mol et al., 2010b). These studies have thus shown that self-care – like care more generally (Danholt and Langstrup, 2012; Mol et al., 2010b) – is always in one sense or another a materially mediated activity, and this materiality involves more than the specific tools for selfmanagement prescribed by health professionals (McDougall et al., 2018). Self-care may be said to be established through often hidden "care infrastructures" – that is socio-material arrangements that extends beyond the single site and activity and enables and constrains how care practices can be performed (Danholt and Langstrup, 2012; Langstrup, 2013). Building on these insights, in this paper we will not distinguish between (self-initiated, immaterial) self-care and (prescribed, material) self-management, but use the term self-care practices as an analytical lens to explore the specific socio-material arrangements through which children deal with a chronic disease in the context of everyday life.

Despite the growing literature on socio-materially embedded selfcare among adults living with a chronic disease, little progress has been made to uncover children's socio-material practices of self-care. This might be because children are generally not seen as agents in their own treatment: management of their treatment outside hospital is delegated to parents or other adult caregivers. From this perspective, self-care only becomes an issue as the child grows into adulthood, taking over the formal treatment responsibility from the adults in their lives – termed "transition" in the pediatric literature (Stinson et al., 2014). However, as already mentioned in the first section, children do have their own experiences and concerns in relation to their disease and its treatment (Hanghøj and Boisen, 2014; Venning et al., 2008). Moreover, the analysis presented here take as a given that all (self-) care is an accomplishment of a collective of human and material entities, rather than the acts of isolated individuals. Even adults practicing self-care for a chronic disease do this with the help of other people (Pols, 2012). At the same time, it is reasonable to believe that children – given their specific social, material, emotional, developmental and bodily realties – do have specific ways of engaging in, learning about, and living with a chronic disease. It is therefore disconcerting that so little scholarly interest has been given to the socio-material self-care practices of children. Children undergo immense transitions, and are repeatedly moving boundaries through learning and re-defining who they are. This means that children's involvement with materialities might be linked to different kinds of previous experiences, practices and norms than those of adults. There is thus a need for a child-centered analytical perspective on how socio-materiality shapes the specific context of activities, responsibilities and norms affecting children's experiences of growing up with a chronic disease, and their opportunities for self-care.

2 Methodology

2.1. Study setting and participants

This study explores the daily lives of children affected by hemophilia and JIA in Denmark, reporting on data from an ethnographic PhD study on the implications of designing eHealth for children living with chronic disease. In a pre-fieldwork phase, participatory observations and recruitment of child patients, and their accompanying family members, took place at pediatric consultations in hemophilia centers of two hospitals in Denmark, Rigshospitalet and Skejby, as well as from the Department of Pediatrics and Adolescent Medicine for

Rheumatology (Rigshospitalet). It was through these hospital settings that a total of 19 children and their families were invited to participate in the study. The children and their families were not selected based on their use of particular technologies, but only on their willingness to participate in the study. Two adolescent JIA patients (age 16 and 17) declined to participate, with the explanation that they did not wish to place any more focus on their disease. The remaining 17 children and their families confirmed their participation in the study after a short introduction to the study's objective of establishing knowledge about how it is to be a child living a with chronic disease. In the following six months, the researcher visited the families at home once. One family left the study after the ethnographic visit, as the parents wanted to keep their circumstances and experiences private. A total of 16 children and adolescents between age 7 and 17, and 39 family members participated in the study resulting in more than 300 pages of fieldnotes and 100 photographs. The fieldwork took place between December 2017 and May 2018 and was carried by the first author (henceforth, the "researcher"), a trained ethnographer with a background in techno-anthropology.

All the children in this study were treated at home mainly through regular injections or oral medication. All the children with hemophilia, except from one, have severe hemophilia and are treated with replacement clotting factor intravenously several times a week, besides on-demand treatment in response to acute bleeding episodes. The children with JIA receive different types of treatment raging from no current medication to regular anti-inflammatory and immunomodulatory injections or oral medication. As prescribed treatment was mainly articulated as "medicine" and condition as "disease" by the children this article will make use of these terms.

The project did not require ethical approval according to Danish law (§14). However, it was reported in accordance with the rules set forward by the Danish Data Protection Agency and the EU General Data Protection Regulation. All participants received information about the study prior to giving consent. Informed and written consent was obtained from all participants upon the agreement that their identities would be not be revealed, and that they could withdraw from participation at any time.

2.2. Data generation and analysis

The initial plan was to follow the children over time and in various everyday contexts. However, as the children expressed concern about the unwanted attention that peers would pay to the disease if followed by a researcher, coupled with families saying the disease should not "take up too much space", these plans were revised. Instead, the researcher visited the children in their homes once for up to 4 h. The study thus faced limitations in exploring socio-material practices outside the homes, instead relying on descriptions given by the children. Similarly the study was limited by only observing home practices of treatment and other domestic practices with each family during one visit. Findings thereby rely on the families' descriptions of the consistency and variations of these practices rather than on observing them more than once.

The early finding of the importance of limiting the attention to disease turned up regularly throughout the fieldwork and became a focal point in the observations and analysis. The home visits became a methodological mix of participant observation and informal conversations. During these ethnographic visits, the researcher participated in domestic activities, play, and had long conversations with the children, and sometimes with the parents, about their everyday life. The researcher initiated visits by targeting questions at the child often in the presence of parents and siblings who complemented the child's memory and participated in discussions, which provided insight into the child's emergent engagement with self-care practices. This methodology effectively became fertile for producing knowledge about "things" in everyday self-care practices, including the role of interior design, routines, family dynamics, responsibility and sense-making about challenges. The fieldwork produced ethnographic insights into the children's lived reality, phenomenological sense-making and ontological and epistemological negotiations about the disease – documented in field notes. Photography by the researcher was used to complement fieldnotes for analysis of specific situations.

Drawing on our conceptual framework, the material was coded thematically (Attride-Stirling, 2001) in Nvivo 11, generating 15 organizing themes. Some of these organizing themes pertained to struggles in living with a chronic disease, tactics towards struggles, disease space, technology and imitations. These five organizing themes make up the substance of this paper and were grouped together under the global theme: "children's socio-material self-care practices". Further analysis of the thematic cluster revealed that the children were in particular preoccupied with three disease-related struggles: treatment anxiety, dependence on parents' management, and feeling different from peers, all of which they tentatively responded to by changing practices and involving specific materialities. We frame these active responses as: 1) editing the script of home treatment, 2) learning to become a treater by playing imitation games and 3) normalizing among peers. In the following we will present these situations of struggles and responses and draw a picture of how socio-material self-care practices help children manage life with a chronic disease. To highlight the interconnected nature of their self-care practices, we will center the presentation of findings on Mathias, incorporating experiences from other children to further explain our findings.

3 Findings

3.1. Editing the script of home treatment by arranging bodies and materialities

All the children with hemophilia, and the majority of the children with JIA, require regular injections at home in order to limit risks of damage and pain in their bodies. This home treatment is a stressful procedure, as we saw with Mathias earlier, who used to be terrified of the home treatment procedure. He struggled with needle anxiety as did most of the children in this study; some started vomiting at parents’ mere mention of “treatment time”. The families struggle with establishing settings and routines for home treatment, juggling both meeting safety standards and calming down their distressed child. In response, families commonly created and optimized the setup for home treatment by arranging various everyday life technologies and the medical equipment to limit anxiety. This was also the case of Mathias, who was 11 years at the time we visited him:

> Mathias put a huge amount of anesthetic cream on his chest half an hour before the injection. He's now lying on a quilt on the dining table with no shirt on. He's very focused, not moving his eyes away from the smartphone in his hand while the father prepares the medicine on the kitchen table. The father puts on rubber gloves. He wipes away the anesthetic cream from Mathias' chest and takes a needle that is attached to a tube with a plastic mechanism in the end. He tells Mathias to lower his left arm and relax it. Mathias stretches his legs and left arm. The father asks if Mathias is ready. They agree they're ready. Mathias counts “1-2-3-now” and the father puts his fingers on Mathias' chest, fixing the port-a-cath [an implanted device under the skin making it possible to inject the medicine]. While the father pushes the needle through the skin, Mathias' abdominal muscles tighten, and he pinches with his fingers the skin on the right side of his chest nearby a scar from a former port-a-cath. The father attaches the syringe to the mechanism on the tube and opens the plastic lock making sure that blood is flowing into the tube. He then injects different fluids to clean the tube and takes out the needle. Mathias, who was quiet until now, urges his father to hurry up; “There's only four minutes till football practice” he says. One of his friends is already

> over there, he says, which he knows from Snapchat on his phone. The father places a plaster on the skin and Mathias rushes out the door.
>
> Field note on Mathias, 11 years old, haemophilia

In this home treatment session, Mathias, his father, and various materialities play specific roles and collaborate to make the treatment happen. The parent, needle, syringe, tube, medicine, saltwater, gloves and anesthetic cream are social and material actors that literally make an inter-outer-connection between Mathias' body and the surroundings, allowing blood and medicine to flow between them to transform his body from physically vulnerable to having the same health status as his friends on the football field. It all follows a well-rehearsed script, which accounts for the way that a certain technological setup is designed to work. The medical equipment forms a framework for practice together with the actors and the space in which they act (Akrich, 1992). The family has drawn on information from healthcare professionals, guidelines and practical experience to design this particular script through a long process of trial and error. In early attempts of practicing home treatment the situation was characterized with Mathias' fear. The medical equipment, the subjugation of his body, and the father's clinical role were out of place in the home setting and thus experienced as dangerous (Douglas, 2003), manifesting in feelings of anxiety for Mathias. The pinching of his skin and tightening of his abdominal muscles are signifiers of the tough mental and physical control Mathias performs in seeking, in turn, to control the underlying fear of the injection. Crucial in finding a tolerable setup for the home treatment procedure was, according to Mathias, the introduction of a new item: an anesthetic cream limiting the pain of the injection. Mathias linked the moment of hearing about the cream to his willingness to “give it [home treatment] a second chance”. On the day of our observation, he was still preoccupied with the necessary amount of cream to apply prior to the injection, and the duration of its effect. Furthermore, he was the one to suggest lying on the quilt on the kitchen table instead of the couch, which had caused him to be unpleasantly pushed down into the cushions when injected, and the counting of “1-2-3-now” when feeling ready for the injection.

These seemingly small changes to the procedure offered him the opportunity to experience the treatment session anew and have a say about how to do it right. The cream, table, quilt and counting, plus the smartphone as mental point of attention, got written into the script of the home treatment session for the purpose of caring for Mathias' wellbeing and prevention of his anxiety while submitting to treatment. From Mathias and his mother's descriptions of past treatment procedures and observing current procedures we understand that they edited the script to reach a stable form for the treatment session. Mathias' role in designing the script was thus crucial to his ability to engage confidently in the home treatment. Similar observations were made with the other children living with hemophilia, and those children living with JIA who also need injections to prevent swollen joints. The majority of children in the study demanded that injections were carried out by a particular parent, and had specific requirements regarding the manner of the performance and setup of home treatment. Jonas, a 13year-old boy with hemophilia, insisted on watching TV and doing his “morning communication” of responding to friends on Snapchat while his mother gave him the injection. Carl, aged 7, with JIA, had a serious needle anxiety, so the hospital suggested an oral treatment solution. Carl explained how he insisted on spraying the substance into his mouth with a syringe himself, to limit the spread of the nasty taste in his whole mouth. Irrespective of their chronic condition, all the children observed thus had bodily and mental experiences with the materials and parents involved in home treatment, over which they could feel reasonable control. These experiences witness instances of reciprocal adjustments of relations and actions between the human actors and technical objects and their environment – to use Akrich's (1992) terminology: to find a stable script to both care for the minor body health status and keep anxiety at a distance. With Pols and Willem's (2011) notions on taming healthcare technologies to fit the practices of the user, we can regard home treatment as a scripted setup that serves the purpose of taming unpleasant and dangerous technologies by domesticating them and grounding them in the home setting, while at the same time changing the child's status from vulnerable in the uncontrollable outside world to a child with injury chances similar to their peers'.

In summary, home treatment is often characterized by struggles with anxiety for children living with a chronic disease, and is thus as much about caring for the child's mental wellbeing as for their health status. Through the trial and error of involving different items and changing associated practices, the families establish a script of best practice to tame the dangerous medical technologies and procedures. The children in our study emerged as agents as a result of the collective work that went into editing the script of items and practices to forms that allowed them to engage with their otherwise objectified bodies in home treatment.

3.2. Learning to become a treater by playing imitation games with equipment and toys

Because of the complexity in treatment, symptom detection and home treatment equipment, the children above the age of around 10 in this study articulated that they often depend on their parents beyond what is culturally assumed among their friends. When the children reach the age of around 12 there is a push from healthcare professionals, parents and their surrounding social network for them to start taking on the actual home treatment practices themselves. A Scandinavian study shows that responsibility for self-treatment in minors with hemophilia is on average obtained at the age of 14.1 years but with significant adherence drops as a consequence (Lindvall et al., 2006).

The children of this study expressed irritation at being unable to attend sleepovers or school camps without their parents visiting to give injections, and frustration about dependence on parental assistance in disease-related practices they felt they should be able to handle themselves. A respondent, Sarah, (age 17) with JIA reported being taught to inject herself at the hospital, however it had lately become a struggle since the change from seven-day to ten-day intervals between injections limited her “feeling of a sense of routine with injections” and her mother had to assist her again, she explained, which “felt like a defeat” for her. From a young age (around 8 years) the children are often encouraged to take on small tasks in managing their disease (e.g. putting on anesthetic cream, sterilizing, putting on plasters or mixing the medicine). However, challenges are also associated with obtaining these skills. A mother reported that her son with hemophilia (age 9) got anxious about ruining the medicine when trying to mix it. It happened a few times that they had to discard very expensive medicine because he did it wrongly. Finding ways to confidently learn to self-manage injections, medicine, hygiene, communication with the clinic, tracing symptoms and so on is thus challenging and spans many years of these minors’ childhood and youth. We will return to the case of Mathias to explore his process of learning self-care practices in response to these struggles to achieve independence from his parents.

Earlier the same day Mathias showed us a treatment kit, identical to the one they use in home treatment, that he played with and used for treating a doll borrowed from his sister. He demonstrated the home treatment procedure on the doll:

> There's a port-a-cath, just like the one under the skin of Mathias' chest, attached to the doll's plastic chest. Mathias puts on adult sized rubber gloves. He shows how to disinfect and then he pushes a needle into the port. He explains how to inject the medicine with the syringe and tells me that he has to clean it afterwards with saltwater and heparin. He makes sure to open and close the tube with the yellow plastic mechanism before and after injecting something new. When he's done he tells me that he'll put the doll and kit in his room because he'd actually like to practice a little more later on. When we go back down to the kitchen Mathias tells me that he once tried inserting a needle in a plastic arm with plastic veins in it, on a family weekend for children with hemophilia. But it went wrong, he tells me in a serious tone, because another child accidently bumped into him and he pricked himself in the other hand with the needle.
>
> Field note on Mathias, 11 years old, haemophilia

The above excerpt bears witness to playful interaction with the otherwise scary treatment equipment that we encountered in the real home treatment situation earlier. The majority of the respondents reported playing with treatment kits and teddy bears or dolls when they were younger. A mother said she thought her son with hemophilia (age 9) plays these games to achieve a feeling of familiarity with the medication. She observed how the teddy bear reacted during the play sessions, reflecting how her son currently felt about the home treatment. In the beginning he could not get himself to prick the teddy bear, but now it is okay, even though “the teddy bear is still not pleased about it”. A mother of a minor with JIA (age 8) had observed her daughter playing with a doll, forcing it down and brutally stabbing a needle into it, thereby shockingly realizing how her daughter experienced the situation of being held tight and injected. Many of these play sessions had expanded narratives, such as a boy with hemophilia (age 7) reporting how he once imagined that there were many patients (teddy bears) that were sick at once, and that he had to work night and day to treat them.

We term these child play-sessions with the medical devices “imitation games”. Play is often encouraged by caregivers, health care providers and children nurse specialists to help children cope with unpleasant symptoms and treatment (Clark, 2013), however we found imitations games to be critical in helping the children learn to manage their chronic condition. We therefore focus on the children's actual practice of play and role taking. Initially we noticed that the children in their imitation games enact another role than in the real home treatment situation: the role of the treater instead of the treated, and thereby the becoming of more than a patient. While it is not surprising that children imitate others' practices, and take on different roles in play (Parker-Rees, 2007), we additionally noted in Mathias' imitation game a preoccupation with the material details of the injection, but an absence of the material items that were otherwise crucial for him in the real home treatment: the anesthetic cream, the quilt, the smartphone and the counting. The non-presence of these actors in the imitation game may indicate what Mathias regards as important and non-important to explore and learn about. The cream, quilt, smartphone and the counting might not be of interest in his exploration because they are actors already known to him through close interactions at every treatment session and because they are not associated with the clinical portrayal of being a treater in health care providers' demonstrations and parents' actual performances of how to treat. Thus he might ascribe these elements to the role of the treated and not relevant when he acts as the treater. As Mathias and all the other children playing these imitation games grow older, they will have to perform both the treater and the treated roles. To learn about the treater role, they use a proxy for themselves in the form of a doll or teddy bear. In the real home treatment situation, the children cannot know the full script of relations between devices and bodies because of their objectified state of lying still. In the game they can fill this knowledge gap of the treater role and otherwise integrated or hidden infrastructure and practices (Danholt and Langstrup, 2012) of the home treatment by organizing a network of actors whose interactions they can explore through play. While playing they may be concerned about how the medical devices work in another way than when being the treated. When Mathias pricks himself with the needle during an imitation game it is a clash between him playing and the real thing; a matter out of the imitation script where he was supposed to be the treater and not the one whose skin was pricked. In that situation he might learn what was otherwise hidden for him in the objectified state on the table, namely that there has to be peace around the injection moment.

Through play the children learn to adopt the perspectives of different actors and spaces, and see how they work together. As Mol et al. (2010b, p. 14) state: "[…] engaging in care is not an innate human capacity or something everyone learns early on by imitating their mother. It is infused with experience and expertise and depends on subtle skills that may be adapted and improved along the way when they are attended to and when there is room for experimentation." To learn to care happens in a continuous shift between observation and experimental adaptation.

Similarly, the children change their perceptions of treatment equipment and skills in their self-created experimental laboratories for disease selfcare practice training. For instance, Louise, age 13 with JIA, explains how she used to play being a doctor who would "make everything good again" in situations that she herself experienced. She used to bring her stuffed bunny-rabbit with her to treatments at the hospital and had conversations with it during and afterwards. At home, she would ask the bunny if it had pain anywhere or experienced nausea, and then inject morphine into its paw with a syringe just like the physician had done to her. She and the bunny had a nice time together in all that, she explains, concluding: "It's good to get it all out and solved this way". The iterations of the games conjoin learning from situations of interactions with parents and healthcare professionals, such as mixing the medicine or injecting into a plastic arm, in a back and forth manner. This helps the children draw more accurate knowledge about proper practices from the adult space into the creative imitation space and vice versa.

Many of the children participating in this study struggle with achieving timely disease self-care practices and independence from parents because of complexity and anxiety in treatment practices. In response, with a doll or teddy bear as proxy patient, the children play imitation games, forming a manageable, domesticated, and confident environment for experiments of what it takes to be the treater and what it means to practice care.

3.3. Normalizing among peers by hiding signifiers of disease

When asked what their diseases were about, the children replied in terms of differences and similarities between their own and their peers' bodies, and were preoccupied with being normal. Here Mathias describes what hemophilia is:

> Mathias explains that if he and someone like him who doesn't have hemophilia is injured in the same way, in the same bodily location and gets a bruise, his [Mathias'] lesion will be much bigger … more swollen. When probed about how it feels to have hemophilia he says "I feel like normal" and "I can do the same things as others – I just have to go home sometimes". He exemplifies this with an episode at football practice where he jumped in front of another player who accidentally hit Mathias' lip causing a small rip. Mathias then had to go home to get it fixed, but could return to practice afterwards. If he gets injured in school, he puts on anesthetic cream and calls his mother to pick him up. They then go home and wait for the father to come home and give the on-demand-injection.
>
> Field note on Mathias, 11 years old, haemophilia

What we want to highlight here is that Mathias does not regard himself as different from other boys his age, and that remission in symptoms is associated with the home domain. When his health status is similar to that of peers he finds himself in a normal state, whereas if his body is injured he has to return home. The majority of children with hemophilia and JIA participating in this study articulated themselves as normal until disease symptoms cause absence from school and physical activities, intervening with their efforts to be just like their peers. However, the children with JIA frequently experienced joint pains which, because of the invisibility of this bodily state, caused peers in the age group above roughly 10 to respond with suspicion and accusations of exaggerating and using the diagnosis as an excuse for getting attention and special care. Some children with JIA above the age of 10 reported being bullied if drawing attention to their disease.

These experiences point towards underlying norms of not standing out or calling for attention in this age group, confirming other scholars' findings that adolescents living with JIA are preoccupied with "being a normal teenager", both socially and behaviorally, where "normal" means fitting in with and acting like peers, and not drawing attention to themselves (Cartwright et al., 2015). The minors with hemophilia did not experience these accusations because teachers and parents had most often explained to classmates about the seriousness of the disease. However, this focus on the seriousness and risks of hemophilia often led to unwanted attention and positioning of the minor with hemophilia as "different". On these grounds, we identify a struggle with being different from peers. As a response, the majority of the children above the age of 10 developed tactics for limiting attention to disease and appearing as normal as possible among peers. Whereas the "differentness" of sitting on the bench during gym class is hard to do anything about for the children of this study, they attempted to avoid other "outstanding" instances caused by the disease. For instance, a girl with JIA refused an extra set of books in class, to limit the weight of her backpack and pressure on her joints, otherwise this would make her stand out as different. A boy with hemophilia tactically covered surgical scars. Others kept medication in their backpacks, out of sight of peers. The fact that the children try to actively manage the visibility of bodily signs, symptoms and disease "paraphernalia" can be seen as an example of "tinkering" in order to balance the demands of the care infrastructure vis a vis their relations to peers and the value of "normalcy".

As all children in this study had a rich social life on online platforms, and as we witnessed Mathias using social media during home treatment, the study aspired to explore how their online social lives form part of their self-care practices, a subject area neglected in former studies on minors with chronic diseases. Interestingly none of the respondents shared anything about their disease with their social networks online, except for rare occasional private messages to trusted family members or friends. The children were generally puzzled by the researcher's questions about sharing anything about their disease online as they saw social media as being about fun and presenting your best self, which did not include their disease or treatment. Mathias did not report on Snapchat that he was getting treatment right before football practice. Instead, he used social media to keep track of who was already at practice, preparing to participate as normal after his injection. Common to these examples is the intentional hiding of signifiers of difference from peers, limiting how much their peers would notice their differentness.

Responding hemophilia families were all members of the Hemophilia Society and had previously participated in organizational events but currently only one family did. For JIA some families had been involved with patient forums when the child was diagnosed or when symptoms were bad.

After learning from organizations and other forums the majority of parents however rejected unnecessary disease activities in order to “limit the disease space” and let other practices, roles and dynamics dominate. This parental privacy and distance towards patient organizations might have affected the children to also abstain from involving others in condition-related matters and confine their disease to private spaces. Thus, the parents' non-engagement in patient organizations and the children's non-involvement of peers are possibly interdependent and complementary practices of making room for more valued activities in the family.

Contrary to the tactic of hiding, a few of the younger children talked about intentionally displaying disease-related technologies to focus attention on the disease when feeling a need for care and attention from peers: these children would deliberately display bandages, wear mittens out of season to keep joints warm, or bring a teddy bear they received at hospital to tell the associated story in school. Thereby they draw on available items to foster attention when needing, or seeking, extra care. One of the children with JIA who felt really bad about her disease and lacked support from peers explained:

> Other people really have to believe you, because you can't show them [the pain and disease], because if you were to show it, you'd need a lot of machines, and it's only the doctor that has those.
>
> Field note on Luna, 11 years old, JIA

The lack of “machines” associated with her condition was a problem for her, as others were then not able to see that the disease was for real. Certain materialities, such as medical technologies, are thereby perceived by the children to be authoritative signifiers of their experiences of having the disease and justify attention from peers. However, these are not always available to the children.

In summary, the pre-teen children and teenagers with chronic diseases in this study struggle with being positioned as different from their peers. They strive to deflect attention away from the disease when it is in a somewhat stable state by downplaying its significance. However, for children with JIA, the invisibility of their disease, the absence of signifiers and disease-specific technologies, make it difficult for them to mobilize recognition and care from peers.

4 Discussion

In this paper we adopted a child-centered and socio-material analytical perspective to understand the context of activities, responsibilities and norms that affect children's experiences and opportunities for self-care. Existing literature on children living with chronic disease not only places limited attention on the agency and self-care of children, but centers around the challenges of transitioning to adult clinical services when adolescents are expected to take on greater disease management responsibilities (Stinson et al., 2014). The focus of this body of literature is on the adolescents' learning to become independent (Kerrebrock and Lewit, 1999) and responsible for adherence to, and compliance with, treatment (McGrady and Hommel, 2013). However, this study has highlighted that there is “always-already-all-sorts-goingon” (Horton and Kraftl, 2006) in children's lives, which allow them to establish self-care practices long before they are expected to do so in the transition age.

Although children are subject to the disease management care of their parents, we found children to play an active role in modifying practices according to their own interests through resistance, suggestions and the involvement of materialities. Their active search for “best practices” results in concessions and acceptance of the otherwise unpleasant procedures because of their exploration of what can be changed and what cannot. Our findings thus suggest that children who edit their treatment script have an improved experience of the treatment as a whole even though some aspects, like the injection, has to be done no matter what. For children to accept unpleasant treatment practices there can thus be no fixed treatment scripts. Self-care in this context seems to be less about complying with clinical guidelines of action, and more about transforming these treatment procedures to something known, comfortable and non-scary, which should be recognized as a central inter-dependent practice of children and caregivers.

We found young children make use of toys and playrooms for changing their relation to technologies, to learn about and experiment with different roles in imitation games of treatment practices, and to detach from unpleasant experiences of caregiver-dependence. These findings are consistent with scholars arguing that play can serve as a safe way to process new information, practice new behavior and experiment with solutions, while stimulating fantasy and creative thinking (Groothoff and Jamin, 2009). We suggest that the playroom might in this regard be seen as an important laboratory for developing knowledge, tactics and domestication. Though the children do not intentionally stage role plays to inform others, observing their play can provide caregivers with insight into current struggles and abilities of the child. Researchers and practitioners interested in children's transition must acknowledge this gradual participation towards independence and learning that happens in pre-transition years, rather than the more scheduled transfer of responsibility and disease management practices from parents to children. Inspired by Clark we call for research on how children's pre-existing imitation games could inspire a space for forming a family ritual to establish shared meaning of a stressful experience (Clark, 2013).

We also observed the children actively avoid attention or appearing different from peers. Some of our older participants tactically sought to hide material signifiers of their chronic disease in both on- and offline encounters with peers. This resonates with a sociological study, which notes that if peers do not see the sick children's treatment devices, they pay less attention to the disease (Monaghan and Gabe, 2015). Conversely, some of our participants expressed a lack of material signifiers to mobilize understanding and support from peers. This demonstrates the importance to children of controlling when their disease is enacted and disclosed to social relations, and when it is not.

We have uncovered socio-material self-care practices that are pertinent to children growing up with a chronic illness. We have highlighted that the practices depend on a host of social and material actors, and that these actors within limits support the agentic capabilities of children to: adapt the home treatment script; develop treatment skills; see home treatment from different perspectives; navigate social norms in their interaction with peers. These self-care practices are not independent acts, but are closely associated with shifting materialities and social relations. The self-care practices manifest themselves variously from child to child, as they depend on the children's various abilities to influence home-treatment practices, their access to and interaction with toys, and the norms characterizing their social networks. Unlike adults, children have a social position as subjects to caregivers and health care professionals' decision-making, which is both limiting but also protecting them from having to navigate and respond to the health care system. However, our study shows that some children do worry about their responsibilities towards the health care system, e.g. when being afraid of ruining expensive medicine or worrying about relying on adult help for injections, resulting in feelings of incapability and defeat. These feelings of guilt of letting down not only themselves but possibly society as a whole (Trnka, 2016) witness how an increasingly neo-liberal health care system engenders economic and individualistic ideas of self-care that the children pick-up on, consequently affecting their engagement in socio-material self-care practices. In contrast to neo-liberal responsibilisation approaches to self-care we echo the call from Clark (2013) for offering children openness towards alternative interpretations, flexibility of meaning and support their agentic capabilities in caring for what they find important within their socio-material relations.

Our findings are constrained by some methodological limitations, which deserve mentioning. First, our study was cross-sectional and only provides a brief snapshot into children's self-care at a particular moment in time. Longitudinal research, unpacking the dynamic and changing nature of their experiences and practices would be useful. Second, the generalizability of our findings is limited and may not apply to other settings, as the structure and delivery of health services in Denmark vary from others. This study only explored the perspectives of the children themselves and their parents. Future research could usefully broaden its scope and include the perspectives and experiences of professional healthcare providers. The ethnographic visits and photography of disease related items however afforded a common scrutinization and objectification of children's physical reality of things and practices in a show-and-tell-manner that seemed to make the them feel relaxed and more equal to the researcher. On these grounds we highlight the value of the socio-material approach, not only as a conceptual frame, but as a method for insight into children's worlds and for supporting children's agency in research about their lives.

Our findings point to the fact that children are engaged with, and respond to, the struggles of living with a chronic disease from a much younger age than currently focused on in much transition literature. While materialities might appear simple and non-technical, their role in enabling different types of self-care practices is far from being simple and non-technical, and their success relies on extensive processes of trial and error and creativity of the children and parents. We conclude that researchers and practitioners concerned with children living with chronic disease can benefit from taking a socio-material and childcentered perspective to uncover children's self-care practices, and in particular consider children's agentic capabilities to edit their chronic treatment scripts; to learn about their treatment through play and imitation games; to manage social relations through material signifiers. CRediT authorship contribution statement

C.M. Bagge-Petersen: Conceptualization, Investigation, Writing original draft. M. Skovdal: Writing - review & editing, Supervision. H. Langstrup: Writing - review & editing, Supervision.

Declaration of competing interest

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Article 2 – under review in Digital Health

Critical user-configurations in mHealth design:

how mHealth-app design practices come to bias design against chronically ill children and young people as mHealth users

Claudia M Bagge-Petersen[1], Henriette Langstrup[1], Jakob E Larsen[2], Anne Frølich[1]

Abstract

Mobile health technologies (mHealth) are increasingly emerging to assist children's and young people's (minors') management of chronic conditions. However, difficulties arise due the realisation of such technologies failing to integrate into minors' lives, leading to a lack of usage and effect. Through this article, we explore ethnographically the design practices of two self-proclaimed 'user-driven' projects designing mHealth apps for Danish patients below the age of 18 living with, respectively, haemophilia and rheumatoid arthritis, and examine barriers in designing mHealth with and for minors. Although the perspectives of minors initially informed these design processes, minors were eventually excluded as users in both projects. Through a concept of 'critical user-configuration', we examine what drove this exclusion of minors from being users of mHealth. Critical user-configuration draws attention to critical moments in design practices where significant shifts in user-configurations take place, shaping who *can* become a user. More specifically, we uncover critical moments: where mHealth-projects expand the group of prospective users; where test-subjects are selected; and where data governance systems and digital health infrastructures are mobilised in the design process. We show that throughout these critical moments there is a drift from user-driven to data-driven design approaches which increasingly exclude groups of users who are less datafiable – in our case minors. We argue that besides giving voice to minors in mHealth design processes, we need to be mindful of the critical moments of design and datafication that become decisive for – often implicitly – who *can* be configured as a user.

Keywords

Minors, mHealth, design, user-driven, bias, critical user-configuration

[1]Department of Public Health, University of Copenhagen, Faculty of Health and Medical Sciences, Copenhagen K, Denmark
[2]Department of Applied Mathematics and Computer Science, Section for Cognitive Systems, Technical University of Denmark
Corresponding author:
Claudia M Bagge-Petersen
Department of Public Health, University of Copenhagen, Øster Farimagsgade 5, Postboks 2099, 1014, Copenhagen K, Denmark.
Email: clba@sund.ku.dk

Introduction

Mobile health technologies (mHealth) targeted at children and adolescents ('minors' in the following) living with a chronic condition constitute an expanding area, and are deemed promising in respect to improving condition management in daily life.[1] Although mHealth is not clearly defined,[2] it is generally perceived as the use of mobile devices, often smartphone applications (apps), for monitoring health-related data enabling the user to assess and improve their own management of treatment, symptoms, and everyday life, in communication with health professionals.[3,4] In some cases, with mHealth, communication between minors and healthcare professionals has improved, fostering engagement, relationship, and trust.[5] However, there is simultaneously an expanding body of evidence questioning the usefulness and outcomes of mHealth for minors.[1,6] Adherence to treatment and improved health outcomes are difficult to achieve in most cases,[7,8] and continuous use and integration into minors' lived reality with such apps often fails.[9] The lack of evidence for either mHealth's integration into minors' lives or for use by minors, has suggested a need to involve minors in the design of mHealth, to ensure such apps are attuned to the lived realities of young people as particular kinds of users. In line with such insights, self-proclaimed user-driven or user-centred mHealth projects for children and young people are, increasingly, including these groups in the design process.[10-12] Still, challenges remain, both due to certain pre-existing characteristics of these groups, and, we argue, due to processes (inherent to digital design) of configuring users. These are processes which do not have the capacity to take the characteristics into account, and which may come to bias design against certain users, even if the group of minor patients were initially cast as central to 'user-driven design'. In this article, we will explore two design processes, both initially aiming at providing mHealth for minors with either haemophilia or rheumatoid arthritis, yet ending up excluding minors as users. By introducing the concept of 'critical user-configuration', we want to mobilise the rich literature in Science and Technology Studies (STS) that focuses on the co-construction of design and user identities. Feminist scholars of STS have furthermore provided *critical analyses* of processes of bias and exclusion in design,[13-15] which direct our attention to what we call *critical moments* in design practices where such biases and exclusions arise. Where the mHealth projects expand the group of prospective users, where test subjects are selected, and where data governance systems and national data infrastructures are mobilised, are all critical moments: we show how these lead to the exclusion of users who are minors. These critical moments each contributed to an increasingly intensified focus on data[16,17] presupposing the user's ability to deal with data, be represented by data, and have access to certain data systems. This produced a user-profile not applicable to minors' particular dependency on caregivers' support in dealing with data; their low representation in datasets; and their incompatibility as data-subjects with certain data systems and data infrastructures. The data-focus of the designs demanded a datafiable user. This in turn came to pose bias against the minor as user of the final design.

In the following, we will first present an overview of the general efforts made within the mHealth sphere to include minors in user-centred design processes; and some insight into what it means to be a child or young person living with a chronic condition. Then we will present our analytical approach, situating our concept of 'critical user configuration' in the rich STS-literature on users and critical moments in design of digital systems. Following an outline of our methods, we will present our findings focusing on three critical moments of user configuration; and finally end by discussing how a focus on these may explain how users otherwise central to design aspiration become excluded and why. Attending – critically – to such user-configuration moments may be of particular importance as digital design is increasingly becoming data-driven, despite still claiming to be user-centred, user-driven, or participatory.

Designing mHealth with and for minors

As the leaders of the mHealth project cases that this article will explore identified their design approaches as 'user-driven', this is the term we will use while being attentive to how such design methodologies help (or do not help) attune the design to minor users. Although it is hard to grasp what exactly a *user-driven* design approach implies[18] it refers in general to a process of collecting various type of information about the user, either by traditional methods, focusing on what people from the intended target group say and think, or with contemporary interdisciplinary design methods, like ethnographic and observational methods that investigate what people do, want, and feel.[19]

Within the field of interaction design, the role of minors in technological design is increasingly moving from that of passive users to participants involved in the design processes.[20] However, researchers have voiced challenges associated with including minors as design partners in terms of power gaps,[21] complex technology and objectives that seem distant from the child's own experience.[22] Furthermore, user-driven innovation is often challenged in continuously involving users and transforming gained insights and requirements into technical requirements of the design (and the other way around) in a multidisciplinary development process.[18] 'Although the user-driven innovation paradigm advocates an open perspective and stimulates the involvement of users from the early development stages onwards, this still contrasts sharply with the narrow and technology-centric scope of many projects' de Moor argues.[18]

Scholars have argued that adaptations in mHealth depend on alignment between values inscribed in the design and values of the patient,[23] and awareness of contextual and motivational aspects of the design.[24] If the design processes do not take into consideration particular circumstances associated with the group that the design is intended for, it might embed barriers in the design, preventing this particular group from using it. For instance, studies have shown that minors and parents hypothesise that the parent will be the main actor performing condition management with a proposed mHealth app,[25] yet that parental involvement and role are neglected in design processes of mHealth for minors.[26] Another example, given by Vinther[4] finds that minors living with juvenile idiopathic arthritis (JIA) felt they had a normal life and did not want to pay more attention to the condition, but that the introduction of a self-management app necessitated a reflective manual activity which increased their thinking about the condition and feeling like patients. Furthermore, Wong et al.[27] argue 'there has been limited attention focussed on how different user-centred approaches identify, select, interact with and assess their "users" [...]'. mHealth-studies rarely account for how patients were engaged, informed the design, or how they were conceptualised as users during the design processes,[27] which leaves the field of mHealth innovation with little experience in qualifying design practices to realise designs useful for minor patients.

The circumstances in which minors live with and manage a chronic condition

Though we have little solid knowledge of what constitutes a constructive design process of mHealth involving minors, their living with a chronic condition is well documented. Living with a chronic condition in childhood and adolescence clearly diverges from that in adulthood, and, equally, condition management differs in a range of ways.[28] First of all, minors are largely dependent on caregivers' decision capacity, power, and capability to support learning about the complexity of their condition, management of it in everyday life, and interaction with the healthcare system.[4] Their assuming responsibility for their own care is gradual and the caregivers' close supervision of management activities can be needed until the age of 18 years.[29] In adolescence, young people must deal with complex issues of maturation while also learning to deal with their condition and treatment.[30,31] Goal setting can be particularly useful for minors' motivation to self-manage their condition,[32] but minors' and caregivers' goals might differ and even clash.[33] Some minors regard their process of liberation from their parents differently from peers', while the parents on the other hand find it difficult to let go of the responsibility.[34] Furthermore, minors' main concern is most often to fit in, and be like 'normal' peers, but their condition follows them everywhere and puts everyday restrictions on them, preventing them from forgetting about it, and disrupting their leisure time, freedom, and social connectivity.[35] Adapting their lifestyle to adherence and strict treatment routines, finding condition management complex, monotonous, boring, time-consuming, and interrupting of their everyday life – all are constant reminders of their condition.[35] To counteract this, young people can perform passive coping strategies like withdrawal, non-adherence to treatment, avoidance of certain activities, and not paying due attention to their bodies, symptoms, condition, and treatment.[35] Their concern with not being different and establishing normalcy is thus associated with suboptimal self-care management.[35] In contrast however, some minors have increased feelings of control by following routines.[35]

Analytical perspective

Configuring the user in designing technologies

Users and their relation to design and technology have received much attention in social science fields. An extensive body of work in Science and Technology Studies (STS) has laid grounds for contemporary thinking of technological innovation and argued that design and 'the user' are co-shaped by numerous social and technical actors involved in the design process.[36-38] Woolgar[39] famously argued that users are configured along with technological design. He accounted for processes where developers define identities of assumed users while also determining what they can and cannot do with the designed technologies. Woolgar's approach has been criticised for merely attributing user-configuration to actions of developers and regarding user-configuration a one-way process, missing that the technology is also shaped by users.[40] However, his semiotic approach focused attention on 'the user' as a flexible imaginary abstraction of who can use the design that is constructed along the design process, rather than a fixed representation of a real individual or group. 'User-configuration' thus implies an ongoing conceptualisation (during the design process itself) of who will be able to interact with, and benefit from, the technology and how. Akrich[41] argued that in developing a new technology, the developers inscribe certain preferences, motives, and competencies of potential users into the design of the product: therefore the final technology contains a 'script', meaning that the technology attributes and delegates certain competencies, responsibilities, and actions to users.[41] This means that all technologies have embedded demands of who can use them, how and for what, and that if actual users do not match these inscribed representations of the user and use-cases, it is likely that the technology will fail. Storni[42] elaborated user-configuration by arguing that purpose, designers, participants, technologies, methods, and the user are mutually constructed during the process of technological design.[42] Furthermore, feminist scholars interested in technological innovation raised awareness of historical and cultural bias in user-configuration that can lead to exclusion of women and other specific groups as users[13,14] and called for various kinds of non-users of technologies to be recognised.[43] Oudshoorn et al.[15] examined the semiotics of how technologies come to be adjusted to certain groups and not to others. They argued that to understand why technologies come to incorporate barriers against groups as users, requires investigation into how users are imagined by designers of the technology.[15]

'Critical user-configuration'

The existing literature has thus critically explored how both human and material actors and larger structural settings shape both design and the user. Little attention has, however, been given to how these actors and settings in practice come to *create bias against particular kinds of users* – despite their being explicitly targeted by, and actually involved in, the user-driven design processes. What are the specific moments at which these users 'disappear'? In our particular case, we wonder how, despite these mHealth projects' striving to include minors as participants in the design from the very beginning, do they come to realise designs that are *not useful* to minors? While existing – particularly feminist – perspectives on user-configuration have enabled a critical analytical stance, we want to add a second aspect of criticality – namely by attending to critical moments in the design process which afford a divergence away from certain user groups. We are here inspired by the work of Kaufmann et al.,[44] who, in their analysis of data intensive practices, introduce the concept of 'data criticality' to draw 'our attention to those moments of deciding whether and how data will exist, thus rendering data critically relevant to a societal context [...]. These encounters, we argue, also require our critical engagement'.[44] While we are focusing on *users*, rather than *data* as such, our analysis will demonstrate that these two can, in practice, become very difficult to distinguish, and that a shift from 'user' to 'data' can in itself become a critical moment of exclusion. With our concept of 'critical user-configuration' we – like Kaufmann et al. – call for attention to certain moments requiring our critical engagement, so as to help us account for the socio-technical constellations in the design processes that become decisive for who becomes the user. Further, we explore how different actors are drawn in to inform the design's purpose and functionality, but in doing so also bias the design towards specific groups and against others – even if these groups seem to be represented in the design method and design ideology.

Study setting and cases

We followed ethnographically two projects that designed apps for continuous condition management of, respectively, rheumatoid arthritis and haemophilia in Denmark, initiated in 2013 and 2015. In the following we use ‘mHealth-supported condition management’ to describe both projects’ design aims: vis-a-vis, to enable the user to monitor, share, read, and act upon correlations between symptoms, treatment, activities, and behaviour in communication with healthcare professionals. The projects were chosen as ethnographic cases because they initially targeted minors as users of the mHealth technologies.

Haemophilia-app for better decision-making in condition management

The haemophilia project was a public-private collaboration between two clinical haemophilia centres, two regional telemedicine centres, a digital health company, and the Danish Haemophilia Society. The project set out to design a digital ‘decision-supporting tool’ (this and following quotations from the projects are translated from Danish by the first author) for all haemophilia patients in Denmark, including children and young people. Haemophilia is a rare bleeding disorder caused by a deficiency of a blood coagulating factor that leads to post-traumatic and spontaneous bleeds. Despite major advances in treatment, patients must endure frequent injections, pay attention to and act upon bleeds, and attend frequent hospital visits.[45] As haemophilia patients mainly treat themselves at home, a driver for the project was to improve treatment plans, ‘optimise the patient’s self-mastering of the condition’, and furthermore support patients in economising their treatment to decrease enormous medicine expenses in haemophilia treatment by enabling patients’ self-monitoring of bleeds and treatment. The project’s design approach was defined as ‘user-driven innovation’, which implied ‘discovering demands during the process in close consultation with the users’. Users were scoped as various age groups of patients living with haemophilia – including a group of 0–18-year-olds – and clinicians of the haemophilia centres.

Rheumatoid arthritis-app for young people’s self-empowerment in condition management

The rheumatoid arthritis-project was a private partnership between a patient association for young people with rheumatoid arthritis (FNUG), a rheumatologist, and a digital health company. The project aimed to develop a self-monitoring app for young people between the ages of 12 and 35 years living with juvenile idiopathic arthritis (JIA) or rheumatoid arthritis (RA) that ‘offered the user a self-insight into the condition, to see correlations in fluctuations of the arthritis and achieve better control.’ 30–50% of minors diagnosed with JIA carry it into adult life. Due to advances in medication, prognosis of the disease has improved. However, symptoms and treatment side-effects still include fatigue, eye-inflammation, joint pain, stiffness, swelling, and inhibited growth.[46] The monitoring was imagined to be useful for the patient him- or herself to gain an overview of the condition, but furthermore to be used as documentation for clinicians. Because the project later broadened its target group to include all people living with arthritis, we will refer to the project as 'the RA project' – which also framed its approach as user-driven innovation.

Comparability between cases

Some differences between the haemophilia and RA projects should be noticed. First, the haemophilia project was conceptualised as a telemedicine project that would integrate into public clinical practices and public data-infrastructures, whereas the RA project aimed to offer patients a self-management tool independent of the public health system, which patients could themselves bring to consultations with their rheumatologists. This leads to the second difference: the haemophilia project would first deliver a finished product with fixed features, and then apply for funding for implementation. In contrast, the digital-health company of the RA project could more freely launch and iterate early app-versions continuously within the scope defined with the patient organisation. Our observations of both a public-private and a private project enabled us to compare them, and generated insight into design practices related to different market strategies, test-approaches and data-processes which nuanced our view on how different structural settings play a part in health-technology design practices and configuration of users, as we will show in the Findings section. Third, the RA project did not include children below the age of 12, whereas the haemophilia project initially did, which limits comparison of the youngest patients across the cases. However, as we are interested in practices of shaping users throughout the projects and the related bias in this, rather than differences between children and young people of different ages, we regard this difference as a peripheral limitation.

Method

Ethnographic exploration of design practice and 'the user'

It was not possible to follow the full design processes extending over several years and involving simultaneous processes of management, economics, politics, technology, markets, and so on, and practices of meetings at different organisational levels, individual work behind screens, and chats by the coffee machine. We therefore aimed to continually take part in activities that in some way involved 'the user' throughout the process. From July 2017 to June 2019, the first author, a trained ethnographer with a background in techno-anthropology (henceforth, 'the researcher'), took part in the two projects by participatory observation of various meetings, workshops, presentations, interviews, and conversations with project members. At that time, both projects had produced and started testing prototypes and early-version apps with users. The fieldwork thus began in the middle of the projects which hindered our insight into previous design phases. However, the researcher gathered and analysed documentation of prior design practices including pictures, presentations, reports on needs and development, evaluations, prototypes, and summaries of participation of patients (i.e. minors). This documentation (or lack of) provided insight into foregoing practices and decision-making, and served as discussion points in conversations and semi-structured interviews with project members to achieve insight into user-configuration practices in different phases of the projects. We saw these collected materials as artifacts that contained embedded meanings of the design and the user. With our ethnographic gaze on, and questioning of, these meanings we aspired to 'open up silenced areas and elevate unheard voices in organisations' and reveal 'neglected issues or forgotten dimensions'[47] and discuss them with members of the projects.

Through thematic network analysis[48] of the documentary material, fieldnotes, and transcribed interviews, we identified and labelled characteristics of 'the user', for instance 'one that needs support when becoming involved in condition management', at different points of the projects. This labelling helped expose how 'the user' changed during the design process. It was not always explicit what 'the user' implied during the design process, because user-profiles, personas and so on were only sometimes described. Furthermore, the change of user did not happen abruptly, but gradually, making it difficult to notice that minors were progressively less fitted to the user profile that the designs afforded. However, we continually checked our material to find out what the changing scopes of the design's purpose, features, use-cases, scenarios, and so on, implied for who could use the design, and related this to the circumstances of chronically ill minors. We found that three design practices in particular drove the configuration of the user away from a profile fitting minors' circumstances: 1) involving clinicians, 2) adult user-testing, and 3) integrating with governance systems for health-data. In the following, we outline these three design practices and show how structural bias towards adult patient circumstances come into critical tension with chronically ill minors' particular circumstances – these being that they depended on support; constituted a minority group compared to adult patients; and were incompatible as data-subjects.

Findings

In an effort to nuance the purpose of the initial design idea, both mHealth projects initially involved chronically ill minors through workshops with minors, to learn about their perspectives and needs when living with a chronic condition. 'Workshop as method' could be discussed in terms of whether this produces correct insights into patients' living with a condition and participants' actual possibility of affecting the initial purpose of the projects. However, we here attend to how this, and other design practices, configured the user. The RA project facilitated a workshop of 12 young members from the patient organisation where challenges in living with JIA were discussed, and solutions proposed via the writing of short notes. The project summarised the expressed needs under the theme 'The disease should not take me over'; and that the final design would 'support young people living with RA in the process of managing their lives along with their condition'. The haemophilia project conducted a workshop with haemophiliac minors (0–18-year-olds) living with their parents (18 participants in total), where participants were asked to draw miniature figures of themselves, sketch places and people related to haemophilia and everyday life, and draw ideas for technological solutions to their challenges on templates, which represented a smartphone, a tablet, and a PC. The report summary of the workshop concluded that 'to increase involvement of the children, support is needed for the parents in how to involve them [their children], but also the development of tools that support the children in exercising self-management. […] To do this early in life will also be more efficient because children acquire new habits and knowledge more easily [than adults].'

The initial design processes thus made explicit chronically ill minors' particular circumstances as depending on support in taking responsibility for, and managing, the condition in everyday life. In the following design practice of involving clinicians in the design process, these characteristics of minors' dependency on support, however, received much less attention, as we shall now describe.

Involving clinicians – configuring the user as a data-provider

Both projects engaged clinicians throughout the design processes to ensure the designs were relevant for clinicians' interaction with patients and assessment of the condition course and treatment plan – patients were still seen as the central user. The haemophilia project regarded clinicians as crucial gatekeepers in making the design feasible, and assured inclusion of their perspective through workshops: here clinicians especially expressed a need for 'insight into whether the patients – in periods between ambulatory checks – comply with instructions for treatment, or if they possibly need counselling and help in adjusting treatment' as this went 'under the radar of the clinicians'. Similarly, the RA project's user-experience consultant explained that their regular meetings with rheumatologists provided insight into challenges in targeting individual patients' actual needs during limited consultation time, and into patients' inability to account for the condition course since last consultation. The design could help 'simultaneously assist [the patient] to get a picture [of the condition] – but also [ensure] that this is a picture that [the patient] can pass on [to the rheumatologist] for shared decision-making', as the CEO explained in an interview. Thus, in both projects, clinicians brought in demands for information about how the condition was actually managed in daily life as a way to improve communication with patients and assess treatment plans.

Furthermore, in both projects involvement of clinicians also enabled the gathering of information about technical and practical settings for clinicians, so as to secure the feasibility of the designs. To do this, the haemophilia project conducted field observations of clinical work processes before, during and after paediatric consultations. According to the project's associated observation report, these observations illuminated clinicians' need to transfer paediatric data to adult healthcare information systems, and for standardising patients' and parents' registrations of treatment and symptoms that were at that time paper-based, deficient, and inconsistent. Based on these insights, the haemophilia project reckoned that 'the shared theme of needs between clinicians and patients was registering and sharing of data'. Patient-provided data would enable 'professionals to offer individualised and personal guidance to patients' and 'offer patients a better insight into their condition course'. Comparably, the RA project collaborated closely with a chief physician and professor in rheumatology to align the design with clinical data-practices, to safeguard that, for instance, 'the pain scale [in the app] is directly comparable to [those in the clinical database]'. Similar to the haemophilia project, the RA project thereby scoped the design purpose as a tool for patients to document various experiences of the condition for 'better insight into their condition' to be used as 'documentation at the hospital', while also 'supporting self-empowerment' of the patients. Both projects' designs were thus associated with improving processes of information quality and quantity which would strengthen the design's integration with clinicians' needs, support assessment of the condition, and daily help patients achieve insight into their condition.

The projects' attuning of the design purpose with clinicians' perspectives gives rise to important reflections concerning how the user was configured along with this. Clinicians' perspectives noticeably focussed attention on 'use of data' rather than 'the user': this brings about a reflection regarding who is positioned as able to predict use of the design. As argued by Woolgar, IT development often replaces ideas of designing for 'what users want' with ideas of future requirements of the technology: '[...] configuring the user involves the determination of likely future requirements and actions of the users'.[39] Clinicians were – by the projects – positioned to speak of imagined futures and potentials of the design because of their role in condition management, medical knowledge, experience in health-care services, and their role as gatekeepers for the designs' integration. Their particular frameworks of time, systems, measures, and data-practices drew attention to the necessity of generating patient data. 'Insight' became the important objective. Here we thus argue that the user was configured not in terms of the chronically ill minors' particular needs, agency, and dependency, but in terms of data fit for clinical settings that took for granted users' ability and willingness to continually produce, share, read, assess, communicate, and act upon condition-related data. That there are often multiple kinds of users with different concerns, purposes, and abilities that can be difficult to align is a renowned challenge.[49] Here, it means a shift in focus from the group that the design was meant for, to a user who could fulfil the purpose of achieving insight into the condition. The user was thus taking the shape of a *data-provider patient*. This shift towards the user as a data-providing subject became a critical moment for minors to fit (or not fit) this outline. Whereas minors' involvement initially in the projects fostered attention to needs for support in becoming involved in condition managing, and support in not letting the condition overshadow the person, little reflection now concerned exactly how patient-provided data would ensure attendant support, or how such data-provider work could possibly demand support. How would, for instance, parental responsibilities for condition management and difficulty in involving their children fit in with this notion of the user as a data-provider? How would generating data that clinicians could use to monitor patients' home condition management affect the distribution of responsibility? Instead of answering these questions, implicit assumptions were made: that patient-provided data would give insights into correlations between everyday condition management symptoms and treatment, increase patients' knowledge about condition causality, make minors involved and responsible, and inform clinicians to improve treatment and communication.

User-tests – the selection of the data-proficient adult user

With these elaborated purposes of facilitating insight into management of the condition through monitoring patient-data, both projects built first versions of the app-designs to test with patients the value and usability of each design. In these test-phases we noticed, in both projects, ambitions to secure the designs' relevance to chronically ill minors. However, as we shall see, attention was more directed towards proving extensive use and production of data with large populations, rather than toward separate age groups. This caused the objections from, and non-use by, the minors who were test-subjects to be drowned out, compared to the majority of adult use-cases.

The haemophilia project drafted first a 'clickable' prototype app, and carried out a series of usability tests with five adult and two young haemophilia patients. These tests were think-aloud tests where the test-subject was given scenarios and tasks for interacting with the prototype, such as: 'It is Saturday, and you have an activity to attend to in half an hour that demands you to be particularly active, and therefore you decide that you should take extra medication. You decide for yourself how much medication you take and register.' The scenarios and tasks of the tests were the same for adult and younger test-users. The prototype contained pre-registered data simulating that the test-subject had been monitoring treatment, bleeds, and activities for a while. In the associated usability report we read accounts of how an 11-year-old boy and an 18-year-old participated as test-subjects, and their experiences with the app. For instance, a graph of bleeds made the 11-year-old to resolve that: ‘I know I have to go to football during these months, and it’s already in this period I get the most bleeds, so I’ll just take my medication all those days.’ In this, we notice that he accepted the premise of reviewing and assessing the test-data. Another screen told him that his average period between bleeds was 32 days and he assessed that: ‘if I get a bleed, just the slightest, and it’s 32 days since, then I can hit it there with a little extra [treatment].’ Here interestingly, but also problematically; he deciphers the number as a prediction for his next bleed to guide his home treatment, while the number rather indicates how well adjusted the treatment plan is. The young test-subjects also expressed disagreement with specific features while referring to their everyday lives. For instance, the 11-year-old found it ‘frustrating to register information for clinical purposes, like activity information prior to taking extra treatment’ as his bleeds could not always be linked to injuries. The 18-year-old stated that he appreciated the lack of condition management recommendations in the app. Yet conversely, he later expressed a wish that the app could change his treatment plan in accordance with his registered bleeds. There was thus ambiguity in whether management recommendations should be generated by himself, automated in the app, or proposed by a clinician. However, these particular ways of reading data and reflections on responsibility distribution with the app did not transfer to the summary section of the usability test report that only referred to *adult* test-subjects’ reflections. In the last test-phase, the project facilitated a pilot-test with 52 adult haemophilia patients, and one parent, but with no minors, to gather information about use in everyday life context and wishes for improvements of the app. The CEO of the digital health-company of the haemophilia project explained in a conversation that the absence in the pilot of test-subjects who were also minors was due to the massive workload in the paediatric haemophilia clinic: the healthcare professional who should have helped recruit paediatric patients was too busy to do this.

The RA project also ran a series of small-scale tests with young people living with RA to iterate the app; but, soon after this, launched an early version app to assess its usability and value with real users. As explained in an interview with the CEO of the digital health company in the project, the data generated with the launched app served as ‘real-world evidence data’ of what mattered to users and what features they used. For instance, the data that the company achieved with the launch would witness what symptoms users chose to track. In his opinion, these data expressed people’s real needs and motivations in real life-contexts, as ‘[…] we can listen in on their everyday life: What is it they are tracking? How do they feel?’ The real-world evidence data could thus provide knowledge about patients, but also serve for continuous assessment of the usability of the app, the CEO confirmed. These assessments of users’ data-productions – downloads, user profiles, and tracking data – however, surprisingly displayed that the app attracted people living with RA much older than the initial target group of 12- to 35-year-olds. Young people did in fact not maintain continuous use of the app. Those who downloaded it merely created a profile and made a few registrations. As the CEO stated: ‘We started off developing for young people, or, with young people for young people, but we have subsequently seen that for a number of older people it looks like it works.’ Herein lies an assumption that the app only creates a value if the user uses it for months to witness patterns in various registered measures. We suggest that the more sporadic kind of use, that young users performed, could possibly be valuable in other senses. However, this did not conform to the perspectives of the project that determined the value of the app and ran their development and business plans by means of continuous flows of data. The sustained usage among older users led the directors of the project to broaden its target group to people living with RA in general, as the CEO explained. In later design work with the app, we further noticed how user-profiling constituted solely adult target users. During a project-workshop aimed at having the app take on the identity of a virtual coach, the researcher noticed that participating employees of the digital-health company and a hired-in coach had older users in mind when discussing users’ possible personal goals as ‘be able to do gardening’, ‘prioritise one’s career’ or ‘be able to play with grandchildren’.

The test-practices of the two projects provided two very different accounts of usability. The haemophilia project’s tests offered insight into the concrete navigations and reflections of users, whereas the RA project’s real-world-approach produced numbers of downloads, continuous use, symptom tracking, and user-profile-data in patients’ lived settings. Both test-approaches aimed to include minors’ perspectives in the tests, but due to different aspects of their user-test-methodologies they ended up driving attention *away* from use by chronically ill minors. The haemophilia project involved two young test-subjects, but did not differentiate scenarios to expose particularities of under-18-year-old test-subjects’ relations to condition management with the app-prototype, or take these insights further. This was despite the test showing uncertainty among the minors as to what the technology was able to do, and what role they themselves would take on as users of it. The issues raised by the two young test-subjects reflected possible non-alignments of the work and responsibility distribution between patient, parents, clinician, and app in the condition management set-up. That the design was to enable patients of all ages seemed to make variations between minors and adults hard to process. Besides that, the pragmatic obstacle of over-burdened paediatric clinicians' being unable to recruit test-subjects prevented their inclusion in the pilot-test, causing the final attuning of the design to rely solely on adult experiences. In the RA project, preoccupation with real life data caused a shift from user-driven to data-driven innovation, inadvertently causing the project to follow what data evidenced as useful, rather than what *missing data* hinted at in terms of *non-use* with the young target-user. The attraction of gaining adult users, moreover, formed the developers' imagination of the user as being an adult in further development activities.

Prior to the test-phases, we had seen an increased focus on data in both projects as means to help both clinicians and patients manage chronic conditions. At the point of the user-tests, data seemed to shift to centre stage in the design practices, and became less the means than the ultimate goal. The user-test methodologies of the projects were in these different ways not set up to differentiate between users being either adults or minors. The user-test methodologies in both projects were instead attuned to *the data-proficient patient* who could generate, read, and act upon data for further development of the apps. This attuning to the data-proficient user thus became a critical moment for the chronically ill minors using the app, because these young test-subjects only constituted a minority of the test-populations, and their difficulties, suggestions, and dropout from the project, thus drowned in the pool of data from adult test-subjects in these data-driven user-test setups.

Integrating with data governance systems and digital health infrastructures – the compatible data-subject

In the final implementation-phase the haemophilia project collaborated with a regional IT architect to secure the design's integration with the Danish health-data governance systems and national digital infrastructures to be able to share data between the patient, clinical systems, patient-records, and databases. Through this collaboration it became evident that implementation required users to use their NEM-ID to log in on the app. NEM-ID is a safe and secure personal log-in for Danish citizens to access public digital self-services. However, only citizens above the age of 15 can obtain a NEM-ID, which meant that minors below this age had to be excluded as users of the app. In discussing this, the CEO of the digital health-company of the project explained that chronically ill minors constituted a much more complex case than adult patients: ‘Often it is not the children themselves who should register, it’s the parents, and they would then register on behalf of the children, and how does one then manage… this legal finesse?’ The complexity referred to the legal position of minors as subject to parental custody, which excluded them from getting NEM-ID and thereby from direct access to, or delivery of, digital health information. This exposed infrastructural challenges in integrating into the design the requirements of patients not legally responsible for their own health and data. In a classic ‘catch-22’ situation, neither was it possible for parents to use their own NEM-ID to create profiles on behalf of their children, as the digital system would automatically link app-data to parents’ own personal health information and not to their child’s health record. Parents can access their children’s health information via sundhed.dk by using their own health profile and NEM-ID, but as in this case, parents cannot use their NEM-ID for health-data tracking of their child. The fact that parents have a digital health profile while also having legal responsibility to take care of their child’s digital health profile posed an architectural enigma when attempting to align the mHealth innovation with existing data governance systems and national digital infrastructures. The above quotation however also reflected an uneasiness in the CEO as to who should and could register experienced symptoms, treatment, and other measures of the child within these domestic dynamics. At what point was the child able to report on their own symptoms? To what extent could parents report on the experiences of their child? The CEO’s proclamation that the parent should monitor on behalf of the minor, however, conflicted with the projects’ initial insight into parents’ expectations that their children could be involved in, and responsible for, management practices with the app’s design.

In the RA project, another digital infrastructural issue emerged as a critical moment for configuring minor patients as users in the further development of the app. The CEO reasoned that the number of app-users was currently limited because the algorithm in the early versions of the app was too simple to provide insights into complex correlations between symptoms, treatment, and daily life, and thus did not really create value for users. This reasoning for non-use depicts a paradox similar to the one pointed out by Cressey, Grint, and Woolgar[50] about developers' wanting users' inputs for what the machine should be like, but at the same time wanting them to interact with 'the kind of machine a user would expect'. The RA project depended on users' tracking in order to realise an intelligent algorithm that included insights users found relevant in their daily living. However, according to the logic of the CEO, users refrained from providing such insights if they did not receive intelligent feedback from an advanced algorithm. Therefore, the CEO explained in an interview, the project was preparing a collaboration with a foreign company and a Danish university to create a machine learning algorithm capable of providing more complex insights for users. To develop the algorithm, the company planned to use machine learning where the algorithm itself evolves by building a mathematical model based on a sample of data. Thereby the algorithm is not simply mathematically constructed by engineers, but depends on input data to improve its performance on the specific task.[51] While the app-data were not plentiful enough to teach the algorithm, the machine learning would be established on statistical properties from cohort data sets in databases of RA patient data. This would allow the app to 'know' correlations of some measures for RA, while it would then find correlations with other measures via the data that app-users generated to find patterns in the symptoms, activities, triggers, treatment, and various personal experiences of the users. The algorithm would thereby provide the user with new insights into their condition. Regarding minors with JIA, this raises an issue of the extent to which paediatric JIA patients would be represented in the databases selected for teaching the algorithm. At the time of writing [September 2021] we do not yet know which databases will eventually be used for this algorithmic work, or if paediatric data will be included; yet it seems crucial to find ways in which the algorithm will be able to distinguish between the statistical properties of minors, youth, adults and possibly any other groups. Regardless of this however, the algorithm would learn to create value for users of the app and thereby amplify the previous de-selection of patients who are minors because of their lack of data-proficiency in the previous user-test setup. What minors would find useful to track, and their particular patterns of app-measures would not be reflected in the continuous learning of the machine learning algorithm. Theoretically speaking, and voiced by other scholars as bias in machine learning (see for instance Sun et al.[52]), the machine learning algorithm would provide insights into 'adult patient condition patterns' because this is what it would continuously detect.

In line with feminist STS scholars' attention to structural bias in technological innovation against specific groups of people (13–15), our point here is that minors' particular restricted affiliation with data governance systems and digital health infrastructures, and their absence from data sets used for algorithmic data work, prevent their representation both in configuration-processes of the user, and in designs for further development. Their exclusion as data-subjects in these data-driven design processes has consequences as to how projects *can* configure this group as users. Whether minors can be configured as users in the process of integrating designs with existing infrastructures, legal regulations, and existing datasets thus depends on how they are already datafied and datafiable, which we would suggest framed as: how they are *compatible data-subjects*. Compatible data-subjects would thus mean a data-representation of a person who fits a given system. When the minor is not represented by data in a system, or cannot access a system to become represented, he or she is incompatible with the system, and this is a critical moment for further configuration of the minor as future user. In our cases, the projects came to configure those groups that were already enrolled as data-subjects in existing data-practices, because these were compatible with the data governance systems and digital health infrastructure for the algorithmic learning, while overlooking users who did not transfer to these digital spaces, namely minors.

Discussion

Design practices critical to user-configuration of minors with chronic conditions

In the analysis, we explored three design practices that particularly configured the user to hold characteristics different from those characterising patients who are minors. With the involvement of clinical perspectives in the design came a demand for patients to be data-providers in continuously monitoring and assessing their condition management, which conflicts with the knowledge we have as to minors' resistance towards regular focus on their condition, and their reliance on support in reading and acting on health information. In the material from the user-tests the distinction between the minor and adult user ceased and the user was configured as a data-proficient patient belonging to a large population capable of generating data for further development of the technologies. In integrating the design with governance structures and national digital infrastructures for health-data, the user was characterised by his or her existing affiliation with and access to digital spaces, which excluded minors because of their incompatibility as data-subjects. We argue that the three highlighted design practices configured the user as: data-providing patients, part of a large data-proficient-population, and compatible data-subjects. This user-profile, while also excluding other groups such as patients subject to legal custody or groups with impaired health literacy, to an especially great extent excludes patients who are minors.

User-driven design involves more than participants in the design process and becomes data-driven

Although the projects initially identified both clinicians and different age groups of patients as their target users, we see that the shape of the app design and the user were instead driven by a broad range of human and non-human actors drawn into the design process at various times.[42] Clinical practices, data-systems, technical infrastructures, safety- and security structures, data-reliant economy and development-strategies, and juristic categorisation became decisive for how the user could be configured along with the design. Embedded in these structural settings were certain scripts for minors and their agency. We find that structural settings of minors are decisive for how they can be configured in these design practices. The user is configured not only by designers or children and young people, but by settings and emergent purposes that accompany the design methods. While the user-driven design practices entail methods of involving stakeholders, user-tests, and integration into data-systems and structures, we argue that these structures also shape the design and the user. The very design methodology of aligning the design with clinical practice, facilitating user-tests, and the integration with data-structures did not set off an alarm when the target group of minors became more and more excluded because the design process focused on those groups that could become represented by data and that would keep the development process going. In turning to data as both a goal *and* a means to design technologies for condition management, we thus identified a critical point at which the design turned away from minors as potential users. The design-methodologies became increasingly more data-driven than user-driven: since the need for sharing data became predominant, the development of the app configured those users who could be datafied – who could be data-providers, were data-proficient and compatible data-subjects. We regard the privileging of data problematic because limitations in existing data-practices, -access, -capabilities and -engagements can exclude specific groups as users of innovation projects that are to deliver certain quantities and qualities of patient-data to prove their effect and economic worth.

Critical user-configuration as a way to expose bias

While inspired by feminist scholars' demonstration of bias in technological innovation towards particular users – for instance towards white highly educated male users[53] – we formed a critical user-configuration approach both to enable a critical analytical stance, and also to focus on moments in the design process that are critical for configuring certain groups of users. This approach afforded insights into mutual processes of configuring users and shaping designs in relation to participants and to structural settings involved in the design process. We continually asked what kind of user these involvements afforded, and how this fitted the initially imagined user. This critical user-configuration approach fostered descriptions of design practices and engagements of social and technical actors crucial for moving the design towards a stable form for condition management.

However, our attention to how the continuously changing user of the projects fitted the minor as user, also spurred us on to ask new questions – in relation to the turns the design took –about minors living with chronic conditions. For instance, minors' dyadic dependency on caregivers, malfunctioning paediatric data-practices, over-burdened paediatric clinics, legal subjectification, and incompatibility with data-systems seem to be characteristics taken for granted regarding minors' situatedness in broader societal structures. However, it is not taken for granted that these factors also constitute *obstacles* when projects innovate digital technologies for establishing minors' improved agency in, and greater benefit from, health services. When observing the technological design, our continued concentration on the issue[54] of minors as potential users of the final mHealth technology, helped to reveal the bias in the design processes. We argue that while attention to technological bias against women, other gender identities and ethnic groups is increasing, bias against children and adolescents living with chronic conditions similarly calls for greater attention. Feminist scholars have argued that 'Technological innovation requires a mutual adjustment of technologies and gender (among other) identities'.[15] Further to this, we find that when it comes to under-age people, technological innovation requires additional mutual adjustment of both technology and the structural circumstances of minors, because it is these factors that become critical in enabling minors to be configured as users. This concerns minors' social boundedness and inexperience with data- and condition management practices. This also concerns minors' personal experience of readiness, or lack of readiness, to take on more responsibility for their own condition management in relation to their caregivers and their lives in general.

Furthermore, our study highlights technical and data-driven methodologies' incapacity to support the sustaining of chronically ill minors as a particular kind of user when it comes to their (lack of) data-compatibility until they turn 18. Minors do not have legal responsibility over their own health, which, naturally, is a protective measure, but which also limits their access to digital health innovation and contrasts with clinicians' and parents' experiences of children's potential capabilities in taking on responsibility for their own health management. However, extraordinary work would be involved in changing these embedded structures around minors to afford their configuration as users in such digital health innovation, and would create other concerns to be addressed.

Our case study took place in Denmark which serves as a specific context in terms of the healthcare system, digital innovation, data governance systems, digital health infrastructures, safety and security measures, and legal regulations. We however propose that critical user-configuration is relevant internationally and beyond the field of digital health, as it requires us to remain focused on technological innovations' initial targeting of particular people as users, and to detect – throughout the design process – critical moments for configuring these target groups as users. Descriptions of these critical moments make explicit the inconsistencies between the particular group, the imaginations of the group, the design, other user-representations, stakeholders, infrastructures, regulations, design methodologies, and incentives of innovation projects.

Conclusion

This article examined obstacles in mHealth design processes that led to the failure to realise a design useful for minors living with chronic illnesses. We found that although our two project cases initially accounted for minors' perspectives, minors were eventually dropped as potential users of the mHealth apps that were, ultimately, only realised for adult patients. We examined what drove this exclusion of minors from being users of mHealth through a concept of 'critical user-configuration': this drew attention to critical moments in design-practices – points where significant shifts in user-configurations take place, shaping who *can* become a user and thus biasing the design towards specific groups, but against others. Through this conceptual framework, we explored the impact of three critical moments: when the mHealth-projects expand the group of prospective users; when test-subjects are selected; and when data governance systems and digital health infrastructures are mobilised in the design process. Any or all of these may lead to the exclusion of certain groups of users – in our case minors – even if initially included as part of a user-centred design process. We furthermore showed that throughout these critical moments a drift happens from user-driven to data-driven design approaches which increasingly exclude groups of users who are less datafiable. We argue that besides giving voice to minors in mHealth design processes, we need to be mindful of the critical moments of design and datafication which – often implicitly – determine who *can* be configured as a user. Furthermore, we want to highlight that mHealth designers should be encouraged to pay close attention to all groups of target users, and to voice any concerns they might have as to difficulties in maintaining particular groups throughout the design process. This could help bring to light any potential bias against particular groups in the context of design, and avoid their being excluded from use of the final mHealth technology.

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Article 3 – under review in Medical Anthropology

Living *ambivalently* with chronic illness

How monitoring of illness experiences makes sense with children and young people

Claudia M Bagge-Petersen

Department of Public Health, University of Copenhagen, Faculty of Health and Medical Sciences, Copenhagen K, Denmark

ABSTRACT

Mobile health smartphone applications (mHealth apps) enable monitoring of patients' illness experiences to seek out how illness interconnects with everyday living and direct attention to patients' individual needs. Considering mHealth for pediatric patients in Denmark, I explore, through focus group discussions, how such monitoring relates to parents', children's, and young people's ways of perceiving chronic illness in relation to everyday life. I show that this group *live ambivalently with* chronic illness and argue that promoting attention to the interconnection between illness and everyday life contrast their attempts to distinguish between *when* to focus on *which* illness experiences.

KEYWORDS: Denmark, children, young people, chronic illness, mHealth, ambivalence

Media teaser: I voice a discrepancy between mobile health technologies' whole-life approach to chronic illness and how pediatric patients perceive their life with chronic illness.

Pathological approaches to patients have increasingly been criticized in Western health care systems by bioethical calls to produce "patient-centered" health care (Sullivan, 2003). This has given rise to digital health technologies in most countries (Organisation for Economic Cooperation and Development, OECD.org) promoted as turning the present *reactive* health care system into a *predictive*, *preventive* and highly *personalized* one through patient-generated data and predictive analytics (Meier et al., 2013). Being proclaimed as one kind of such technology mobile health smartphone applications (mHealth apps) enables through monitoring of various patient experience measurements "to better understand how illness, treatment and care impact the entirety of a patient's life" (Forestier et al. 2019, p. 1). The monitoring of patient experiences can here refer to anything that the patient observes in relation to illness – including "subjective" measures, like pain, mood, and behavior (Cipresso et al., 2012), and more "objective" measures, like how much treatment the patient has undertaken, – to be used for assessing clinical and person-centered outcomes (Browne et al. 2010). mHealth is deemed promising for determining the patient's need (Bruce et al. 2020) while also enabling patients to improve their own illness management (Meier et al., 2013). For instance, patient-reported outcome measures (PROs) are becoming a prevalent way of generating information about patients' experiences of health status, impairment, and health-related quality of life through questionnaires that ask about, for example, daily activities, pain, and anxiety (Kingsley and Patel, 2017). Yet, scholars have voiced a scarcity of knowledge on the impact that digital self-monitoring technologies' can themselves have on patients' experiences of their illness in relation to particular contexts of their lives (Jiang and Cameron 2020).

Within the fields of science and technology studies of digital health, scholars generally emphasize the political, cultural, economic, and discursive dimensions of the paradigm shift towards datafication and quantification of qualitative aspects of life and health (Ruckenstein and Schüll, 2017). Here voices have called for "a better and more skeptical understanding of the seemingly positive turn" (Wynne, 2007: 100), arguing that chronically ill patients' embodied experiences and relation to their illness increasingly are defined by neo-liberal emphasis on the individual's responsibility and self-sufficiency (Charmaz, 2020). Digital monitoring tools are used not only for detection and prediction of health-related issues, but also to shape and modify people's behavior (Mackenzie, 2005; Lash, 2007; Beer, 2009) so that the data that people generate can be processed and fed back for them to modulate their actions (Ruckenstein and Schüll, 2017). As argued by Schüll (2016) this data-monitoring and modulation does not only concern biological life but also extracorporeal elements, like daily choices, rhythms, preferences, and tendencies. Social science scholars have therefore recently attended to how monitoring of different aspects of people's illness simultaneously *shape* patients' experiences of their illness, themselves, and their lives in a certain way (Kiran et al., 2015; Hofmann and Svenaeus, 2018). Furthermore, scholars are raising awareness about people's *ambivalence* towards using digital health technologies arguing that people have both positive and negative experiences with using such technologies in relation to the different environments that they are used in (Marent, Henwood, and Darking 2018; Ruckenstein and Schüll 2017; Lupton 2013).

Though not at the same pace as with adult patients mHealth is also emerging for children and young people in different diagnostic fields (Armoiry et al., 2018). mHealth is for instance reasoned suitable for increasing children's and young people's illness management activities anywhere and anytime, and for providing information about the disease course in the context of their lived reality instead of being limited to the realm of scheduled medical consultations (Frøisland, Årsand, and Skårderud 2012; Rhee et al. 2014). While mHealth is deemed promising to increase children's and young people's ownership over the illness management (Carpenter et al. 2016; Fedele et al. 2017), major challenges persist in proving its adaptation and continuous use as well as effect on health and personal outcomes (Fedele et al. 2017). Furthermore, we generally, have little knowledge on how monitoring patient experiences makes sense to children and young people although such technologies are intended for daily use (Jiang and Cameron, 2020). Vinther (2020), who provided one of the few social science studies in the area, found that while an mHealth app with children suffering from juvenile idiopathic arthritis (JIA), held value at specific time periods at other times it unnecessarily caused them to reflect upon their illness and role as a patient. The general scarcity of such insights is despite the growing attention to psychosocial aspects of children and young people's experiences of the impact of illness in their lives (Brady, Lowe, and Olin Lauritzen 2015), struggles with experiences of differentness, and strategies to heighten their normality such as paying less attention to their bodies and treatments (Lambert and Keogh, 2015).

In this study I explore together with children and young people that live with a chronic illness and some of the children's parents how mHealth makes sense to them. I make use of the concept of *ambivalence* to direct attention to how the monitoring of illness experiences relates to children and young' peoples' and their particular ways of perceiving their illness..

Shaping illness experiences with technology

Mol (2000) argued that technology designed to generate knowledge of the patient does more than passively register facts, as it brings with it a certain way of perceiving the person's health. Furthermore, scholars in sociology, anthropology, science and technology studies, and media and communication are increasingly exploring how the datafication of health and care practices inflict how people experience themselves and their health (Ruckenstein and Schüll, 2017). Oxlund (2012, 53) has for instance argued that a "numerical ontology" pervades everyday practices and "ways in which people relate to their own bodies". Lehoux (2008) argued that there is a recursive relationship between chronic illness and technologies that monitor it, which does not necessarily reduce anxiety as this monitoring makes prominent the unpredictable existence of the condition. Assessing the relationship between the individual and their data can trigger various experiences of doubt, guilt, fear, and disappointment, but also joy, enthusiasm, and pride (Salmela at al., 2019). Scholars have thereby argued how digital monitoring tools also *shape* the understandings and experiences that people monitor. By encouraging focus on illness in situations where patients' thought illness insignificant health technologies can "create illness" where it was not before (Hofmann and Svenaeus 2018).

Living ambivalently with illness

Svensson and colleagues (2020) suggest that to live with a chronic condition might always involve living between different categories of "sick" and "well", "abnormal" and "normal". Within medical anthropology Wahlberg (2017) has drawn attention to an increased focus in health care on peoples' abilities to "live with" chronic illness and initiatives that encourage patients to move beyond categories of sick and normal and into "living with" illness. "What these instances have in common is a focus on patient living as something that can be improved in terms of 'quality of life', 'well-being' or 'healthy life' as therapeutic objects.", he argues (2017, p. 7). This has made him call for attention to consequences of these demands of patients. Other scholars have similarly argued that whereas an "anytime-anywhere" discourse is characterizing initiatives to support young peoples' daily activities, autonomy, and responsibility over their health they on the other hand also impose demands of the user anywhere and at any time (Trnka 2016). Recently scholars have highlighted people's *ambivalence* in using digital health as to counterbalance both fatalistic and optimistic accounts of technology and support a critical scrutiny of digital health interventions (Marent, Henwood, and Darking 2018). Ambivalence is reflected in the unpredictive ways in which people relate to monitoring aspects of their health. People can in some situations feel a sense of control, pleasure, hopefulness when monitoring their health while in other situations feel overwhelmed, frustrated, or disappointed (Ruckenstein and Schüll 2017). The voicing of peoples' ambivalent relationship with health technologies offers a more nuanced perspective on how people move between engagement and dis-engagement and how positive and negative consequences of using these technologies can shift across environments (Lupton, 2017; Ruckenstein and Schüll, 2017). Scholars have besides this proved that patients are not passive subjects of health technologies, but tinker with them (Mol et al., 2010), oppose them (Oudshoorn and Pinch, 2003), and negotiate them in relation to spatial and material arrangements and activities of everyday lives and homes (Langstrup, 2013; Ivanova, 2020). As Pols (2013) argues, the goal of patients is rather to find solutions to live with the illness than to pursue to meet demands posed by health care professionals.

Drawing on the above scholarly works I see a need for exploring children's and young people's sense making of mHealth apps that avail insight into the interrelationships between their chronic illness and their daily life. In presenting the argument in this article, I will show that the children and young and their parents that I encountered *live ambivalently* with illness. This implies that they see themselves as ill and normal, they engage with management of treatment and they do not, they see illness in a bio-medical way and in a self-defining way. I direct attention to how living with illness can necessitate differentiation between *what* illness experiences to attend to *when* as in contrast to perceiving illness as constant, continuous, and connected to the entirety of their lives. Though they do experience connections across illness and the lives they are living, it is not all experiences of illness that can matter all the time.

Focus group discussions of life with chronic illness and monitoring

Through focus group discussions with children, young people, and parents I, a trained ethnographer with a background in Techno-anthropology, enabled insights into their sense making of life with chronic illness and mHealth. Specifically, these focus group discussions were engaging three groups of 18 parents of children living with hemophilia on an event in The Danish Hemophilia Society in September 2019, and one group of 6 of these parents' children living with hemophilia, age 7–14 years, at the same event. Furthermore, I engaged a group of 5 young people, age 18–25 years, living with one or multiple conditions including cancer, heart disease, asthma, hypermobility, spinal cord hernia, and diabetes constituting a youth-panel at Rigshospitalet in Denmark, in a focus group discussion in June 2019. Written informed consent was obtained with all participants after I explained verbally and in writing my aim of exploring how mHealth makes sense to them, that they could at any time raise questions or withdraw from the study, and that they would be anonymized and represented only by pseudonyms in the article.

Focus group discussion enables empirical data at a group level through a collaborative engagement in an activity in the discussion (Morgan 2012). Attention is thus to how the group interacts in discussing an issue of concern, the uniformity and variation in perceptions, experiences, norms, and values among participants, and how participants can move each other towards other standpoints, and why these might differ (Kitzinger, 1994). The researcher's role is less influential on the group (Lehoux, Poland, and Daudelin 2006) and the discourse of the group is likely to oriented towards the group itself (Bourdieu 2020). I provided stimuli for the discussions that could inspire mutual reflections in the groups. With the parents, the stimuli consisted of statement cards (Kitzinger 1994) that would raise discussions about parents' everyday experiences with managing and supporting their children's health and well-being. In the focus group discussion with the hospital youth panel, I presented various discussion topics regarding their illness experiences and the monitoring of such experiences. In the focus group with the children, I presented a series of short open-ended vignettes (Barter and Renold 2000) with fictional child characters living with hemophilia that we would discuss, thereby offering the children to formulate their responses without necessarily referring to themselves while still being able to draw on their own experiences. The vignettes were built on participant observation in the homes of other children and young people living with haemophilia that I had conducted at an earlier point in the overall research project, that this study is part of (Bagge-Petersen, Skovdal, and Langstrup 2020). With the vignettes I endeavored to signify the children's everyday life in our encounter (Koch, Sørensen, and Levidow 2011). I did not probe about individual emotional experiences to prevent awakening negative thought processes that I could not take care of afterwards. This limited my insight into their emotional relationship with their illness, however the parents and the young people provided important insights into this, as I will show.

All group discussions were recorded, transcribed, and coded with attention to how monitoring of experiences make sense to these groups. Emerging themes were grouped through thematic network analysis (Attride-Stirling, 2001) under headlines like “normality”, “learning”, “engagement”, “differentiation”, and “illness space” which all spoke to different aspects of an overall theme of ‘experiences of living with a chronic illness.’ In the following I will present how parents, children, and young people perceived and managed experiences in relation to these themes.

Backgrounding and foregrounding illness experiences

In listening to the discussions among parents I learned that safeguarding normality in raising a child with hemophilia was a high priority besides safeguarding their physical health. Though it is difficult to translate into English, an expression of “limiting the ‘space’ that illness take up” (Danish: “få sygdom til at ‘fylde’ så lidt som muligt”) was frequently used by the parents to account for their efforts in “reducing the attention to illness” given their experiences with illness’ intruding voluminous effect on what these families think about, are concerned about, talk about, practice, and identify with. As one father expressed:

> Frans: You shouldn’t in any way try to pretend [the illness] isn’t there, that is not where I’m going, but I still think it should take up as little space as possible

One of the statement cards that I provided the parents with probed about whether an mHealth app could be used to monitor treatment and children’s experiences of symptoms, energy level, activities, mood, and sleep as to enable insight into how the illness interrelates with everyday life.[i] Hemophilia demands strict control of symptoms like bleeds, and adherence to treatment. It has been shown to affect children’s daily activities and experiences of pain, limitation of physical activities (Limperg et al., 2015) and negative effects on family life, peer relationships and experiences of schooling, well-being and self-confidence (Crawford et al., 2010). Parents' initial response was that it was unnecessary to monitor anything but treatment and symptoms with an mHealth app. The statement card provoked direct resistance and ridicule from the parents:

> Gitte: Well, concerning [my son] it would take up way too much space [*fylde for meget*] if he had to register every day: 'What is my mood, how did I sleep, was I awake?'
> […]
> Helene: Won't it return too much focus on [the illness]?
> Lotte: It's like, it will kind of take over – or it will become the most important, and it's not the essential [thing].
> Helene: It becomes self-reinforcing
> […]
> Irina: We wouldn't need that; we wouldn't download one [app] like that. I'd like one that could register medicine and [efficiency of the treatment in the body], but that about sleep and all that, we don't need that. […] For us, who have well-functioning children, and children that are otherwise all normal, and get to be all normal, we don't need it.

The resistance witnessed a worry that the monitoring would increase attention to the illness. They mainly saw potentials with an app that could generate the, in their opinion, more obvious insight to be used for adjustment of treatment. A few parents raised the point that if measures like mood and sleep could be used by the health care professionals to improve treatment plans, it could be worth it. This would however be argued against by other parents that maintained that it would have consequences for their children to focus attention to these aspects of life. Like the argument of Hofmann and Svenaeus (2018) the term "self-reinforcing" used by Helene implied that focusing on aspects like mood, sleep, energy, or activity as related to illness would amplify the causality ascribed by the child to the impact of illness on these matters. Monitoring could potentially amplify existing hardships, the parents reasoned in different ways:

> Erika: No, that’s too much, because then you’re reminded of [the condition] all the time, right? And we know that children and young people would rather not be reminded about all that.
>
> Frans: No, it’s also so… like if [son] …one of those injuries he’s had, where he can’t walk for 14 days… well, it would be to rub it in his face with an app like that.
>
> Gitte: Then you have to register it! (laughs) […] or ‘how is your mood?’ (laughs)
>
> Erika: God, no!
>
> Jonas: If I ask him […] how he’s feeling, and how it hurts, and something like that, right, then he gets damn annoyed.

The children should not be constantly reminded about their condition by focusing on injuries, pain, sensation, feelings, or mood. Jonas here voiced also that the relationship between parent and child depends on alignment between what experiences to focus on and how. Though the child’s bodily and emotional experiences *are* acknowledged as interdependent, parents choose carefully whether these should be foregrounded, and how. Furthermore, parents found that monitoring could insinuate connections between the condition and experiences that the child might have regardless of their condition:

> Birgit: If [the app] then asks “Why are you sad?”, and it was because he [the son] had a fight with a friend, [he would say] “it’s because I am sick”. That’s the answer I would get. […] well, I don’t think [the children] should get permission to decide what their mood depends on.

Birgit here argued that the monitoring would encourage the child to “decide” how the condition affects him emotionally. The condition would be a scapegoat for other causes of negative feelings, like having a fight with a friend. A father furthermore pointed out that such conversations about hardships should not be addressed by an app, but covered by parental rights and duties in supporting the child’s coping with experiences:

> Kristian: We agree that an app would be able to help with practical things, but I think that these things in particular – mood, sleep, activity, and energy – shouldn't take place on a screen. It should be something to talk about. If he [son] is in a bad mood or didn't sleep well, then we talk about it.

Parents agreed that practical management of the condition can be delegated to a digital space, but experiences of everyday hardships should be placed in conversation within the family. In general, the parents had clear ideas about where to draw the line between "practical" condition-related measures that could be placed with an app, and aspects that are their *parental* privilege to handle. However, the parents broadened their perspectives on what practical issues could imply when another statement-card probed into facilitating children's involvement in treatment practices:

> Frans: You could use it for the younger children to involve them in a way.
>
> Gitte: Yes, like "Where is it that it hurts?", "It's right there!", "Then tap there". Then you could say, "Well, you have a bleed in your elbow – you can see that because it's swollen", and so on – "And how many of those have you had?"

Somewhat like mHealth apps for children and young people are often reasoned in the patient-centered health care paradigm (Carpenter et al. 2016; Fedele et al. 2017), Gitte was here thinking of the app as a pedagogical tool to teach the child to use a particular terminology and logic of symptoms and be alerted to the bodily experience of bleeds, which other parents explained feels like a tickle, tingle, quiver, or movement. Teaching the children to be alert to bodily experiences instead of ignoring them was also a key task of the parents. Gitte later reflected on how monitoring could help correct her son's inaccurate assessment of what triggers his bleeds:

> Gitte: Then you could use [the app] for something practically… if he himself registered [his bleeds] and "What did I actually do to get these bleeds?", … then he would maybe find out that it's not that bad to play football with the other boys in class – that isn't when [the bleeds] happen.
>
> Helene: – to offer some visibility…

> Gitte: Yes, because he’s painfully anxious about participating in those school break activities because he [thinks] he’ll just get injured. If we could then say “We actually have [an app] here that shows that that’s not where you get injured, it’s rather as soon as you get home and jump around on the trampoline”.

According to Gitte, visual presentation of the connection between playing football and the son’s injuries could possibly prove to her son that he could engage actively in physical games with his classmates at school. The monitoring was thereby anticipated to increase the son’s attention to his condition in activities that trigger bleeds, but reduce attention to it where it was not relevant. As also voiced by other parents, it would be legitimate to foreground specific experiences of symptoms and activities that were already recognized as having an impact on the children and family. In an elaboration of the purposing of mHealth for children and young people, the parents thus anticipated that the monitoring could in this sense *help to distinguish between* various illness experiences and focus on those that, in their opinion, assist learning about condition management.

From these discussions I see ambivalence in parents’ ways of relating to their children’s illness experiences. On the one hand, parents teach their children to be alert to particular bodily and physical experiences, and on the other hand, they do not wish to place too much attention on how the condition affects everyday life, so as to prevent their children from feeling affected by the condition, and from not engaging in “normal” activities like football. Their way of responding to this ambivalence is to determine when and how illness is a relevant matter to direct attention to and how. Parents recognized mHealth monitoring as potentially easing the registering of symptoms and treatment, improving treatment plans, and increasing their children’s knowledge about treatment, triggers and bodily sensations. They however resisted monitoring things that did not seem clearly relevant to symptoms and treatment. From their perspective, their children’s sense of normality is endangered by verbalizing and visualizing the condition as connected to what the children do, who they are, and what they experience in everyday living – except if there is a causal reason, like jumping on the trampoline.

One father, however, put forward another perspective, somewhat opposite to the discourse among the other parents:

> Jonas: […] We keep telling [our children]; "Well you can live like everybody else if you just get your preventive medicine – then you can live a normal life like everybody else". We're doing them a disservice [by telling them that] because they can't! […] I don't think it's about making it take up as little space as possible. It's about making it become part of who we are, because it's there all the time. So, it's just them – it's who they are. And a hemophilia app doesn't change that you're a hemophiliac. They are! […] but you can make it a more natural part of the person they are. [My son] is proud of it, he's proud of being a hemophiliac. […] – I asked him: "What if it could just disappear?" "No, thanks!" It is how he is.

The father's issue here is the other parents' pursuit of a normality that he argues cannot be achieved. He calls for acknowledgement that the illness is a "natural" aspect of their children – something close to an identity to be proud of. This father's perspective of identifying with the condition, and accepting one's differentness, resonated with the perspectives of some of the children in some situations as we shall see in the following.

Shifting between normality, coolness, and illness engagement

While the parents were discussing in one room, six of their children, all boys,[ii] aged between 7 and 14 years, joined me in another room to discuss what it implies to live with hemophilia. Over the hour we spent together, I noticed how the boys were noticeably preoccupied with the bio-medical aspects and vocabulary of their condition. Yet, they were just as preoccupied with the importance of their own "normality" in interaction with their peers. The serious attitudes around their diagnosis and their normality were however, accompanied with pronounced fooling around, joking, and laughing:

> Me: So, this is a recorder, and I just turned it on, so that I can listen to what you guys say afterwards. But it's just for me to hear.

> Victor: [leaning towards the recorder] Hi, my name is Victor and I’m 12 years old! […] Listen: I have Asperger’s!

Victor does not have Asperger’s syndrome. It is meant as a joke. Victor goes on to introduce Rasmus who sits next to him and who he knows from earlier social events organized by the Danish Hemophilia Society.

> Victor: This is Rasmus. He’s good-looking and my best friend – so far! He has inhibitor.

Inhibitor is an immune system response to the clotting factor concentrate that renders standard replacement therapy for hemophilia patients ineffective. While Victor introduces his sidekick Rasmus by referring to inhibitor, he is ahead of me before I introduced the task of discussing characters and their challenges in living with hemophilia:

> Me: […] and then I’d like you to find out what happens to this person in the story. So, Viggo! [I show a drawing of a boy]. He’s afraid of home treatment; to get injected at home and get treatment. Why is that?
>
> Rasmus: I know! It’s because he’s ugly! No, sorry, sorry! No, it’s because he feels worried if…
>
> Mads: …his mum…
>
> Rasmus: … if his mum’ll do it right, and if…uhm, if it happens that – and that probably won’t happen but – she hits his artery, or something like that, and that they can’t immediately get to the hospital, where he’s sure that they can give him the right help.

I expected that the boys would mention anxiety about needles and pain (which some of them did afterwards), but not anxiety about parents hitting an artery, which here evidenced Rasmus’s preoccupation with risks of clinical procedures. What further struck me was Rasmus’s shift between joking and posing a quite serious scenario. Both Victor and Rasmus had made jokes about Asperger’s syndrome and being ugly. They continuously brought up such human traits of others, to have a laugh. When I introduced the next fictional character, we came closer to this issue of being subject to personal traits in normative social contexts.

> Me: This is Lasse! He doesn't want to talk to his classmates about his condition!
> Steffen: I don't bother to do that either!
> Me: Why doesn't he want to?
> Victor: Then he might feel different [Danish "unormal"]…from the others…
> Rasmus: I *do* know that I'm different [Danish "unormal"]!
> Ulrik: Because he's afraid that others will laugh at him…
> Me: Okay, yes…
> Steffen: He's afraid of being bullied…
> Me: Okay, and then what happens? What could happen to Lasse?
> William: That he, if he had an accident for instance, then he could… then the other boys might just say, "Well, [get] up again, you'll be fine!" instead of freaking out completely [because the friends would know the risks associated with injuries as he has hemophilia].
> Me: Right, okay, so that they would react a little more coolly…?
> William: Yes!

Victor here states that bringing attention to the illness in relation to classmates can invoke experiences of differentness, and William wants classmates not to react dramatically, but rather like they would with any other child. The boys agreed that they should be careful about disclosing that they are "hemophiliacs" (Danish "blødere") which was an expression they themselves used. Only close friends could be trusted. I furthermore thought it curious that the boys posed this ambiguity between not wanting others to see them as "different" but knowing that they were, as stated by Rasmus, so I probed on this:

> Me: Some of you said that he [the fictional character] wanted to feel more normal…
> William: Yes, so he can say that he's all normal when he gets his medication, because then you're, in principle, as good as normal.

> Steffen: Until you're injured!
>
> Me: So, you could say that to your friends, maybe?
>
> William: That you're as good as normal, but only if you've had your medication. But if he uses [anesthetic cream] it takes an hour and a half – when he's different [because of the time it takes for the cream to have an effect before he can get injected].

Rasmus does not engage in this part of the conversation, as he, sees himself more basically as different, as expressed before. The other boys here voice an ambiguous normality. As William expresses it, normality comes and goes according to coverage of treatment: this is about his blood being able to coagulate in the same way as the others' can – a fact which could be communicated to his peers so as to make them perceive him as normal. The boys seemed to generally agree with this. I here notice that a bio-medical explanation of the illness to peers help avoiding the illness being used to define them as a person – as something that concerns their identity. Normality is thus both linked to being covered by treatment but *also* to peers' recognition of this. They stated that they could be teased by peers because of their illness, and I probed about this:

> Me: And how can you be teased about that? About having a condition?
>
> Steffen: You just can.
>
> Victor: You're different.
>
> […]
>
> Me: Yes, it's not normal to have a condition because most people don't…
>
> Victor: Yeah
>
> Rasmus: I am just cool! (giggles)
>
> Victor: Me too!
>
> Me: But, when would [the fictional character's] friends think he's cool?
>
> Ulrik: When he's being injected!
>
> Steffen: Yes!
>
> [...]
>
> Ulrik: My friends give me great backup when I get injected, they think that…they don't get that I even dare… to go through that every other day!

Here they point out how drawing attention to their regular injections can awaken praise of how cool the boys are – how they enable to do something extra-ordinary. I noticed that the boys use contrasting discourses about themselves accordingly with which social situations they refer to. They speak about their striving for “normality” and “coolness” in relation to peer interaction. In contrast they speak about themselves as “being hemophiliacs” among each other in the focus groups. The boys talked with each other about their experiences with hemophilia A and B, inhibitors, and exchanged knowledge about different treatments and methods. Inspired by Bourdieu (2020) I see this as an expression of their opportunity to constitute an inside-group that shares unique traits in opposition to an outside-group of peers that they otherwise have to make an effort to become part of.

Towards the end of the session, I provided them with the scenario of a group of fictional children who were designing the worst ever hemophilia app. The boys were very creative in suggesting how the “worst” app would, for instance, make a knife come out of a phone to cut you, or make you jump out of a building, give an electrical shock, or show a head being cracked open. When I then introduced the scenario of a group of children who created the “best” hemophilia app they were quite serious about the task:

> Tor: You could learn how to get injected in the arm.
> Rasmus: Yes! So that you could learn.
> […]
> Ulrik: An app that could say how much medicine is in your blood.
> Victor: Wow, that would be smart!
> Rasmus: Yes!
> Ulrik: Because then you’d know when to take your medication.

The boys thought that a good mHealth app would support their bio-medical and practical knowledge about treatment. They reckoned that a timely visualization of how the treatment covers them would help them manage the condition. The boys were in general very enthusiastic about knowing how the condition works in a bio-medical sense and about becoming able to administer treatment. When I closed off the session, the boys expressed that they would have liked to know if the characters had hemophilia A or B because this influences the treatment plan, how they should handle the condition, and what the app should say.

The boys' experiences with their illness were characterizes by ambivalence in terms of how illness can shift between getting in the way of their purposes, arise appraisal, and serve as an engaging subject to investigate, learn about, and talk about with other children living with the diagnosis. As a complementary point to the review of Lambert and Keogh (2015) that shows that children and young people generally find illness management complex, time-consuming, inconvenient, boring and interrupting their everyday lives, I found that this particular group of boys were highly enthusiastic about their diagnosis and treatment in a bio-medical perspective *in some* situations, like this group discussion.

Balancing illness engagement and increased illness awareness

Rigshospitalet in Denmark has an established youth panel of young present or former patients serving as a reference group for assessing health care initiatives for young patients. Throughout my group discussion with this panel, the young people were preoccupied both with becoming more involved in decision making around their treatment, and with being supported in their own dealing with the illness' effect on their lives. On the other hand, they were concerned with how a fulfilling of these wishes would increase their attention to the illness' impact on their daily lives and make them feel more like ill persons.

The youth panel initially shared their experiences regarding the visibility of their conditions, which varied between them. Like Lambert and Keogh (2015) show, the young people voiced that other people's awkwardness around them made them uncomfortably aware of their own conditions, causing them to reduce attention to it as much as possible. These were experiences of other people staring, asking inappropriate questions, or being artificially silent around them. Like with the boys in the previous findings section, some of the young people made use of a bio-medical discourse when answering other people's questions about their condition to avoid talking personally about it:

> Nadia: I don’t tell [them] everything, and I think that you at some point start distancing from it [the illness], and tell things in a more ‘doctor’ kind of way, where you just tell some facts and then that’s it. And then you don’t touch upon how you’re feeling about your condition, but more like what it is. Like that, it gets easier because then you avoid the “Are you going to die?” or “Can you even survive?” or like such excessive pity. […] But on the other hand, then you might suddenly feel very alone with it, because the others don’t know *how* it is – they just know *what* it is.

The curious thing here is that a fact-based discourse around the condition can help background personal experiences of living with the condition. However, Nadia recognizes that her feelings need addressing too, and she feels alone with it when people around her do not know what she is going through, which is also confirming the review of Lambert and Keogh. Another struggle extensively expressed by the young people was the issue with becoming involved in their own illness management especially when transferring to adult health care services:

> Oliver: It can be very hard for the young person to move to the adult health care services without having been told what his condition is and how he should do his treatment, like just being thrown into it without knowing anything. So, I will just suggest that the child or young person should be involved throughout the whole [disease course], because then the transition is easier.
>
> Nadia: […] it also makes it easier that the children themselves can explain how it is, because they are the ones who have [the condition].
>
> Oliver: And also, the treatment you get, right, like what good does it do? It’s important for the young person and teenager to know what he [*sic*] is taking, like what good it does. If they can’t feel anything, or if [the treatment] has a long-term effect, then the young person… that goes for me at least, then I didn’t bother to take the pills because I couldn’t feel it immediately.

Obtaining the adequate competencies and knowledge about the illness is challenging. In line with the aim of mHealth to increase young patients' learning of illness management (Carpenter et al. 2016; Fedele et al. 2017) the young people here voice a lack of involvement that prevents them from learning to attune their experiences of symptoms and treatment to the effects of the treatment plan. The youth panel criticize not being drawn into the conversations that concern them which makes them feel that control is placed outside their own reach. I probed about how they imagined that mHealth apps that aims to monitor *their* experiences with the illness could assist their involvement and learning about their own illness. In response Nadia reflected on a point in her life where she was to take on more responsibility for managing the condition:

> Nadia: I've always had asthma and I said to my mum; "Now it's my turn [to take responsibility]", but the doctor didn't really want to let me. So, there I was, not really supported, and then it was a struggle to take it on myself. […] I think an app would be a good way of doing it [get involved], because you might have a bit of control.

Nadia here is concerned with support in taking control when the health care professional is not attentive about including the child or young person. Between the lines of what she is saying seems to be that and mHealth app could help authorize the child's involvement – offer something that makes the child capable of convincing the health care professional to include them. The youth panel agreed that an mHealth app might be able to assist involvement and support in taking responsibility for the condition and treatment, however, it was difficult to say exactly how. I offered some concrete examples of mHealth apps with various diagnosis that make possible to monitor treatment and symptoms, and mHealth apps that aims to give insight into illness' correlation with daily life activities and general well-being. This made Nadia question the incentive of monitoring anything at all given the chronicity of her illness:

> Nadia: I think maybe there's this thing about chronic patients: you will never be cured! So, it could be that after you have [used the app for a while] you'd need an incentive or else it might feel a little pointless. Despite [the app] being good and working well, you can end up like, "Well, either way, I'll never be cured, so what's the point?" […]

> I could imagine that if it [the app], for instance, states that everyday I have to say how much pain I have today, I might think; “Why?” I’ll also experience pain in a month and in three, so…

The constant of “chronic” is an issue for Nadia, and she questions the chance of monitoring resulting in any changes to her own situation. In confirmation of the anticipation in the parent’s focus groups and Hofmann and Svenaeus’ (2018) point about shaping illness experiences by monitoring them, Nadia and Petra anticipate that monitoring can amplify feelings of being ill:

> Petra: If I had to sit down every day and pay attention to, like really feel, how am I really today, then I think I would feel more ill than when I just carry on with it.
>
> Nadia: Then you’d have to think hard about it and then I just think that in the end you’d just become a little bitter, I think.
>
> […]
>
> Nadia: I think that… the thing about professionals wanting to know “how you are” and “when” and “bla bla bla…” – Where what we want, is more like “how can I *deal* with it, and how can I live an ordinary life with it?” […] I certainly don’t need to voice my limitations every day. […] I think that my need for an app would be more to, like, help find out “well, what do you do with that?” – Not that it should be a cure, but more like… because, there has to be an end goal, that it’s not just to report “this is how it is,” but more so that there’s something in it for the ill young person, so that it’s not just like, “well, today I felt bad just as usual”.
>
> Petra: Definitely! It becomes a very negative view on life that you, like, take up if every day you sit down and say, “Well, I couldn’t ride my bike there and I had to stop and, oh…” like it’d be a bit depressing, right?

The young people here voiced how monitoring of various aspects like symptoms, triggers, daily functionality, and mood could be counterproductive for their general view on life. At the same time Nadia voiced that her priority would be to learn to “deal with” such aspects of how the illness impact her everyday life. Here the other panel members seemed to listen carefully to Nadia and silently agree. Though what “dealing with” implied was not all clear seen from my perspective, Nadia voiced her need for support as something that is beyond what “the professionals want to know” and thus, in this sense, as a matter that is not considered by health care services.

The discussion with the youth panel was limited by a non-specificity in terms of what an mHealth-app would monitor in each diagnostic case of the young people and what kinds of action could be taken from the generated information to improve their daily challenges. However, the discussion brough forth their current struggles, ways of seeing their lives with illness, their wishes for improvement, and perspectives on illness monitoring on a general level of their own engagement in illness self-management and relationship with health care professionals. On the one hand they wished for more direct involvement with the health care professionals and with their illness management. On the other hand, they were reluctant to provide information that they were not certain could be used to improve their health or their ways of coming to terms with their illness in daily life, because monitoring had to be held against its increasing effect on their thinking about how ill and limited they are.

Ambivalent anticipations of mHealth enabled monitoring of illness experiences

I have above directed attention to the ambivalence it implies for parents, children, and young people to live with chronic illness. With this attention I enabled insight into how various experiences of illness are not merely connected to everyday life with this group but connected *in certain ways* accordingly with the different social situations, activities, wishes, logics, and normative settings that they encounter as part of their lived realities. My study contributes to an understanding of how parents, children, and young people respond to the ambivalence of living with a chronic illness. They have various ways of balancing engagement with their illness against not letting the illness intrude the whole of their existence. They strive to differentiate between *when* and to attend to *what* aspects of illness. Related to this, Lambert and Keogh showed that as a response to the experience of “differentness” children and young people can obtain strategies to achieve a sense of normality. As an elaboration of this, I argue that the children of my study have strategies that enables them to care for *both* the illness and for other aspects of their lives. This suggests that though children and young people might want to engage with their illness in a more informed way this has to be done in accordance with the many other concerns in their lives where illness cannot always play a significant role. Pols (2013) argued that people most likely strive to find ways to live with the illness. Similarly, the young girl Laura so nicely put it: “what we want, is more like ‘how can I deal with it, and how can I live an ordinary life with it?’” The ambivalence in this statement is however strong. The word “deal” can both imply “managing the condition” to obtain an ordinary life or “managing to live with illness” to obtain an ordinary life. To find out how to best live with chronic illness implies ambivalence and finding out how to prioritize when to focus on illness and when not to for these young people.

With my findings I am pointing to new reflections on how monitoring of illness experiences make sense with children and young people. Similarly with Salmela and colleagues’ (2019) study on monitoring technologies with adults, I found that parents children and young people associated monitoring of illness with experiences of enthusiasm, engagement, pride, and increased illness, limitation, and differentness. Vinther (2020, p. 188) showed in her study how an mHealth app increased children’s experience of illness (JIA) because the self-management of symptoms changed from an “automatic to a reflective” activity with the app. Before using the app the children would, most often, not experience themselves as patients as much as “soccer players, horseback riders, school children, and so on” and carried out self-management practices in an automatic manner (Vinther 2020, p. 277). In my study the anticipations of the parents and the young people was similarly that the feeling of being ill would be increased by an app that draws attention to the interconnectivity of illness and different aspects of life. Much in accordance with the arguments of Hofmann and Svenaeus (2018) my findings suggest that illness experiences can be amplified by monitoring of them and can appear in situations where this group otherwise strive to delimit them. Yet, Vinther’s study furthermore showed that the children living with JIA and the parents anticipated that an app could be useful in situations where they experience unknown and worrying symptoms or treatment side-effects as to obtain insight into correlations between the illness and sensed experiences. Similarly, in my study the perspectives of parents and young people suggest that some specific illness experiences can be relevant for determining how to administer treatment accordingly specific symptoms and triggers that they find have a causal effect with their health state.

On this background, I suggest that mHealth innovation's ambition to avail a "better understand how illness, treatment and care impact the entirety of a patient's life" (Forestier et al. 2019, 1) and an enablement of children and young peoples' illness engagement anywhere and anytime (Frøisland, Årsand, and Skårderud 2012; Rhee et al. 2014) seem mistuned to the complex processes of determining when to direct attention to various implications of the illness with this group. The claim I am making is that mHealth innovation should consider how children and young people differentiate between the illness in accordance with other aspects of their daily lives to free up capacity for experiences other than those related to illness. Like other scholars (Kiran et al., 2015; Hofmann and Svenaeus, 2018) I argue that mHealth design also shapes the very experiences that it seeks to monitor which can potentially be troublesome for children, young people, and parents. I furthermore call for further research into children's and young people's sense making of mHealth monitoring based on concrete cases.

Declaration of Conflicting Interests

The Author declares that there is no conflict of interest.

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Notes on Contributors

Claudia Bagge-Petersen has a background in Techno-anthropology and her research interest is in digital health innovation for children and young people that live with chronic illness. She is currently obtaining a PhD-degree at Section for health Services Research, Department of Public Health, University of Copenhagen.

https://orcid.org/0000-0001-9373-4545

Notes

[i] The monitoring measures included in the probing statement card did not reflect an actual hemophilia-app. Currently an mHealth app *is* being developed for hemophilia-patients I Denmark, which enables patients to monitor treatment, bleeds, and triggers. More information can be found here: https://www.rm.dk/sundhed/faginfo/center-for-telemedicin/projekter-og-indsatser/Beslutningsstotte-i-bloderbehandling/

[ii] Although there are also females diagnosed with bleeding disorders, hemophilia is far more prevalent among males.

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Field guides

Field guide with minors

Feltarbejdeguide til børn med kronisk sygdom

Overordnet:

- Følg sygdomshåndteringen for barnet.

Fokus:

- Hvordan er barnets sygdoms-hverdag konstrueret? Hvilke aktanter relaterer sig og hvordan?

Delelementer:

- Følg sygdommen? Symptomer
- Følg smartphonen/iPaden /spillene/legene/data/medicin
- Er der teknologier der bruges anderledes end forventet?
- Har teknologierne uforudsete konsekvenser? Hvad var de tiltænkt og hvordan bliver de brugt? Hvilken indflydelse har de på hverdagslivet? Har noget ændret sig?

ANT:

- Downstream – hvordan bruges taktikker allerede? Er der forandringer, kontinuitet eller er der åbninger og leakings?
- Hvilken (hverdags- og familie-) historisk kontekst relaterer sig til sygdomshåndteringen.

Field guide with the projects

Feltarbejdeguide til eHealth-projekter

Overordnet:

- Følg eHealth-løsningens tilblivelsesproces.

Fokus:

- Hvordan scriptes bløder- og gigtbørns hverdagsbehandling?

Delelementer:

- Hvordan bliver **patientens** behov til en ting i appens konstruktionsproces?
- Hvordan bliver **familiens** behov til en ting i appens konstruktionsproces?
- Hvordan bliver de **sundhedsprofessionelles** behov til en ting i appens konstruktionsproces?
- Hvordan bliver **bløderforeningens** behov til en ting i appens konstruktionsproces?
- Hvordan bliver **journals** behov til en ting i appens konstruktionsproces?
- Hvordan bliver **andres** behov til en ting i appens konstruktionsproces?

ANT:

- Upstream – skabelsesberetning for en eHealthløsning
- Streaming – overførsel af løsning til brugere
- Skabelsen af et netværk/black ”babushka” boxes.
- Hvad skal der til for at stabilisere netværket? Hvilket stabiliseringsarbejde finder sted? Hvilke aktanter bidrager? Hvilke bidrager/indgår ikke? Tegn netværket af aktanter.
- Hvordan ændres løsningen løbende? Af hvilke aktanter og hvorfor?
- Hvordan er barnet/patienten aktant i tilblivelsesprocessen?
- Hvilken historisk kontekst relaterer sig til designprocessen?

Interview guide with CEO’s in the projects

(This is the example with the JIA-project. The inteviewguide with the hemohlia-project was very similar)

- Interesse: hvorfor mange eHealth-løsninger til børn og unge ikke bliver brugt og hvad der udgør en god designproces, som skaber et brugbart redskab for børn og unge med kroniske sygdomme!
- Diktafon…
- Forventningsafstemning omkring hvordan jeg må repræsentere Daman som case.
- Hvor tæt er du som CEO på designprocesserne af RheumaBuddy og HealthBuddy-løsningen?

Hvilke antagelser og viden har udviklerne om børn og unge med kronisk sygdom?

- Hvad er særligt ved at udvikle eHealth til unge? (muligheder/barrierer)
- Hvilket problem skal appen løse? (for de unge, for Daman, for pharma, for rheumatologer) Hvordan kan appen rumme dette på én gang?
- Appen dokumenterer nogle sammenhænge og giver overblik men, hvordan bevirker det at man laver en forandring?

Hvorfor er det svært at udvikle noget der virker til børn og unge?

- Hvilke udfordringer har I for tiden med udvikling af appen? Hvad ville I gerne være skarpere på?

Hvilke praksisser har udviklerne for at designe til børn/unge? (co-creation, brug af data etc.)

- Kan du opridse designprocessen for RheumaBuddy? Hvilken design-strategi? Er den blevet anderledes end I først havde tænkt? Hvilke successer og fejl har I oplevet? Hvad er I blevet klogere på undervejs og hvordan?
- Hvilke typer viden har I opsøgt?

Hvordan konceptualiserer udviklerne det unge kroniske liv og hverdag?

- Hvad skal I vide for at udvikle til unge?
- Er der noget særligt ved designprocessen til RheumaBuddy som ville have været rart at vide inden? Ift. unge? Hvad skal man overveje, når man udvikler til jeres målgruppe?
- Hvorfor ikke udvikle til børn? Hvad står i vejen?
- Hvordan involveres fremtidige brugere i designprocessen? Hvordan ved I hvad de unge har brug for? Hvem kender de unge?
- Hvad tænker du at de unge ser som gevinsten af denne app?
- Hvorfor er logbog og scoring godt for deres liv med kronisk sygdom?
- Hvorfor er det godt at dokumentere gode og dårlige dage? Kan det ikke gøre at man bliver nedtrykt?
- Ændrer appen ved sygdomsopfattelse og livet med JIA? På hvilken måde?

Begreber: Hvad mener udviklerne self-care og self-management og empowerment er i forhold til de unge? Hvordan kan det understøttes af en eHealth app?

- Hvordan tænkes andre aktører omkring barnet ind i brugen af appen?
- Hvad er den gode ”management” for unge? Og hvad er svært for at opnå den? Hvordan hjælper appen?
- Hvordan er man ”empowered”?
- Hvad mener I med ”holistisk”? Hvad indebærer det? Hvorfor disse parametre? Hvorfor lige til denne sygdom og målgruppe? Hvordan kan det holistiske dataficeres og gøres til viden?
- Hvordan er appen til gavn for andre stakeholders?

Analytisk problem: hvilken praktisk rolle skal appen have ift. ”chronic living” og ”patologi”? Fare for sygeliggørelse af hverdagen? Når den unge bruger appen, er det så meningen at det man tracker skal ses som subjekt eller objekt?

- Hvilket forhold til sygdommen forsøger jeres app at få den unge til at have?
- Hvad er det appen skal ændre i den unges forhold til sygdommen?
- Hvordan ser du forholdet mellem sygdom og hverdag i appen?

Mulighed for eksperiment, imitation, afprøvning, leg og ændring af narrativer?

- Bruger brugerne appen på andre måder end I først havde tænkt? (fx community, buddy)

Data

- Hvilke data er I interesserede i og hvorfor?
- Er der nogle data I har valgt fra?
- Hvorfor har I valgt fra at tracke medicinsk behandling? Skal data samkøres med andre data? Hvordan er det overhovedet interessant for pharma hvis ikke der er behandlingsdata? Hvordan lærer pharma af de data I indsamler?
- Er der nogle eksisterende studier I kan sammenholde jeres data med?
- Hvilken viden har I fået ud af data indtil videre?

Algoritmen

- Hvad er en machine learning algoritme?
- Hvem sidder med den i praksis? Hvordan er du indover som CEO? (Proxus og ITU)
- Hvorfor er det nødvendigt?
- Er den færdig? Hvad skal den kunne?
- Er der nogle begrænsninger ved denne tilgang?
- Hvordan sørger man for at algoritmen bliver god?

- Er der nok data til at algoritmen kan lære sig selv op? Hvad har den lært/ikke lært endnu?
- Får I også data som I ikke havde tænkt på? Eller ikke regnet med? Hvilke anvendelsesmuligheder er der for fx fritekst? Hvordan lærer algoritmen af det?
- Hvilket output fodrer I den med? Hvordan kan den finde nye ko-relationer når outputtet er kendt? Har den fundet nogle sammenhænge I ikke kendte i forvejen?
- Fejl er en del af dens lærings-proces, men der er ikke noget script – så hvordan evaluerer I dens performance? Hvordan lærer I og algoritmen af fejl?

Syntetisk data

- Hvad er syntetisk data? (en slags personaer?)
- Hvorfor skal I bruge det – hvorfor er det ikke sikkert at bruge rigtige data?
- Kombineres syntestiske data med anden viden om sammenhænge mellem symptomer eller udelukkende rigtige brugeres data?
- Kan der ikke være bias i de oprindelige data (fx first-movers)?
- Begrænsninger ved syntestisk data?
- Andre fordele end sikkerhed og privacy?
- Kan de skalleres?
- Kan du tegne for mig hvordan machine learning og syntetiske data fungerer? Ift input, output?
- Er der noget særligt omkring børn og unge og syntetiske data eller er det metoder I ville benytte på alle målgrupper? Hvorfor?
- Kan jeg se algoritmen , data og syntetiske data?

- Bruger I slack? Kan jeg se jeres interne kommunikation?

Focus group guide minors

Focus group-guide med børn med hæmofili – sygdom og normalitet i eHealth

Problem: eHealth design inddrager ikke viden om børns problemstillinger, værdier, normer, self-care praksisser og brug af eksisterende materialiteter. Vi ved ikke hvordan eHealth-løsningerne skal forholde sig til familiernes adskillelse af sygdom og normalitet. Vi ved heller ikke hvordan en designproces der åbenbarer disse praksisser og materialitet ville se ud.

Formål:

1) At facilitere kreativ fælles forestilling om og diskussion af, hvordan brug af materialitet og teknologi ville kunne løse problemer omkring hjemmebehandling, læring af self-care praksisser og interaktion med jævnaldrende

2) At undersøge børnenes fælles forståels- og meningsudveksling af datagenerering, symptom- og medicintracking og håndtering til deling med sundhedsvæsenet og eget overblik og læring

3) At generere viden om børn og unges underlæggende normer omkring adskillelse af sygdom fra det normale og hvordan eHealth-løsninger vil relatere sig til denne adskillelse af hverdags- og klinisk domæne

4) At udforske hvordan metodologisk konstruktionen af et fælles laboratorie for kreativ tænkning omkring udfordringer og løsninger kan fremme viden om normer, praksisser og narrativer i børnenes hverdag med sygdom og bidrage til eHealth-innovation

Metodologi: fokusgruppe med børn. Et konstrueret socialt laboratorie for at undersøge hverdag, sygdom og teknologisk innovation for børn med hæmofili.

Forskningsspørgsmål: Hvordan optimeres sammenhængen mellem eHealth design praksisser og mindreåriges levede self-care praksisser af at holde sygdom til specifikke situationer? Hvilken metodologi ville være gunstig for eHealth-udvikling?

Arbejdsspørgsmål:

1) Hvilke kreative løsningsforslag genererer børnene omkring stikkeangst, læring af behandlingspraksis og interaktion med jævnaldrende?

2) Hvad tænker børnene om at generere og dele data om deres sygdom og håndtering af den? Hvad tænker de om eHealths formål om at give overblik og læring?

3) Hvilket ritual/situation tænker de eHealth ind i? Hvor kan det ikke indgå? Hvordan har det betydning for normativ adskillelse af hverdag og det kliniske?

4) Hvordan fungerer stody completion play narrative metoder til fremme af eHealth innovationsprocesser?

Form: Workshoppen skal udformes så den reflekterer, hvordan vi så børnene tilgå læring, inddragelse og rolletagning under feltarbejdet; dvs. de har mulighed for at inddrage forhåndenværende teknologier og ting fra normal hverdag og sygdomsrelateret, og forestille sig narrativer og forskellig rolletagning. Der tages både udgangspunkt i værdier, normer, problemer og løsninger fremkommet blandt familierne under deltagerobservation og eHealth-projekternes antagelser om problemstillinger og løsninger og værdier omkring holistiske sammenhænge, kroppen som et kort, læring gennem registrering. Spørgsmålene er formet som historier med en åben problemstilling som børnene i fællesskab uddyber og bearbejder; material story-completion.

Medbring: consent-formler, diktafoner, Ting til bordet: A3-papir, en bamse, en dukke, et medicinsæt, en nålepude, en telefon, en computer, postits, tuscher, papir, en papkasse, en skotøjsæske, slik, bolde, slime, en taske, et aktivitetsarmbånd, ur, et køleskab, et bord, bandage, tape, en medalje, plusplusser, figurer der repræsenterer fiktive bløderbørn, navneskilte, billeder fra mit feltarbejde, ikoner af sociale medier og spil. Smarties og modellervoks

(Spørg organisatorerne om jeg må låne ting fra stikkerummet)

14.15-15.15

Introduktion:

Hvem er jeg?

Vi skal lave historier sammen om nogle børn og unge med blødersygdom. Jeg har fundet på starten af historien ud fra det som nogle andre bløderbørn har fortalt mig om deres liv og oplevelse af at leve med hæmofili.

I må meget gerne inddrage tingene fra bordet, eller ting I kommer i tanke om i historierne. Læg det gerne på det her papir og tegn eller skriv på det.

Ikke én rigtig historie – bare sig hvad I tænker, der sker for det barn vi snakker om. Brug sætningen ”det kunne også være at…”

Varm-up:

Runde med navn, type hæmofili og yndlings-spil

Historier/dilemmaer omkring problemer, taktikker og teknologi:

1. <u>Hvilke kreative løsningsforslag genererer børnene omkring stikkeangst, læring af behandlingspraksis og interaktion med jævnaldrende?</u>
    a. Viggo er bange for hjemmebehandling. Hvorfor? Hvad sker der så?
    b. Lasse gider ikke at snakke med sine skolekammerater om sygdom. Hvorfor? Hvad sker der så?
    c. Max vil gerne selv stå for sin sygdom i stedet for hans far og mor. Hvorfor? Hvad sker der så?
2. <u>Hvad tænker børnene om at generere og dele data om deres sygdom og håndtering af den? Hvad tænker de om eHealths formål om at give overblik og læring?</u>

d. Sune ved godt at medicinen hjælper på blødninger, men han har alligevel mange blødninger. Han vil gerne forstå hvordan hans blødninger hænger sammen med hvornår han får medicin og de ting han ellers laver. Hvorfor? Hvad sker der så?

e. Mark kommer ind til lægen og lægen vil gerne vide hvornår Mark får medicin og hvornår han har blødninger. Hvorfor vil lægen gerne vide det? Hvad sker der så?

f. Emma har nogle rigtig dårlige dage, hvor det hele bare er rigtig nederen. Hvorfor? Hvad sker der så?

3. <u>Hvilket ritual/situation tænker de eHealth ind i? Hvor kan det ikke indgå? Hvordan har det betydning for normativ adskillelse af hverdag og det kliniske?</u>

g. Tom familie har snakket om at ”hæmofili ikke må fylde for meget”. De forsøger kun at snakke om sygdommen på nogle bestemte tidspunkter. På andre tidspunkter snakker Tom slet ikke om sin sygdom. Hvorfor? Hvad sker der så?

h. Der er nogle børn med blødersygdom der har fået den sjove ide at lave den værste app man overhovedet kan forestille sig til børn og unge med hæmofili. Hvordan ville den værste app være?

i. Bagefter vil de gerne lave en god app, hvor man kan finde ud af ting omkring sin sygdom. Hvad kalder de appen og hvad kan den? (hvem skal bruge den, skal lægen se det, skal forældre?)

Tid til at spørge ind til nogle af de indsigter og ideer der er fremkommet!

15.15-15.30

- Fælles snak i plenum om highlights af det der blev snakket om.
- Hvordan synes I workshoppen var?

Focus group guide parents

Focus group-guide med forældre – sygdom og normalitet i eHealth

Problem: eHealth design inddrager ikke viden om børns problemstillinger, værdier, normer, self-care praksisser og brug af eksisterende materialiteter. Vi ved ikke hvordan eHealth-løsningerne skal forholde sig til familiernes adskillelse af sygdom og normalitet. Vi ved heller ikke hvordan en designproces der åbenbarer disse praksisser og materialitet ville se ud.

Formål:

5) At facilitere kreativ fælles forestilling om og diskussion af, hvordan brug af materialitet og teknologi ville kunne løse problemer omkring hjemmebehandling, læring af self-care praksisser og interaktion med jævnaldrende

6) At undersøge forældrenes fælles forståels- og meningsudveksling af datagenerering, symptom- og medicintracking og håndtering til deling med sundhedsvæsenet og eget overblik og læring

7) At generere viden om forældres underlæggende normer omkring adskillelse af sygdom fra det normale og hvordan eHealth-løsninger vil relatere sig til denne adskillelse af hverdags- og klinisk domæne

8) At udforske hvordan metodologisk konstruktionen af et fælles laboratorie for kreativ tænkning omkring udfordringer og løsninger kan fremme viden om normer, praksisser og narrativer i forældrenes hverdag med sygdom og bidrage til eHealth-innovation

Metodologi: fokusgruppe med forældre. Et konstrueret socialt laboratorie for at undersøge hverdag, sygdom og teknologisk innovation for forældre til børn med hæmofili.

Forskningsspørgsmål: Hvordan optimeres sammenhængen mellem eHealth design praksisser og mindreåriges levede self-care praksisser af at holde sygdom til specifikke situationer? Hvilken metodologi ville være gunstig for eHealth-udvikling?

Arbejdsspørgsmål:

5) Hvilke ”struggles” ser forældrende i børnenes hverdag med hæmofili og hvordan indgår materialitet til at fordre/udfordre self-care praksisser? Hvilke innovationer, der taler ind i etablerede praksisser, kunne forældrene forestille sig?

6) Hvad tænker forældrene om registreringer, data og deling med sundhedsprofessionelle ift. at få et overblik og lære om sygdommen? Hvordan forestiller de sig at det i praksis skulle foregår i deres hverdag? Hvilke nuværende praksisser skulle en digital løsning tale ind i? Hvordan skulle børnene inddrages i sådanne praksisser?

7) Hvordan tænker forældrene at en holistisk eller en klinisk app ville relatere sig til deres norm om ”at sygdom ikke må fylde for meget”?

8) Hvordan er denne metodologi omkring diskussioner af eksisterende praksisser, normer og nye teknologiske muligheder ved hjælp af statement/dilemma/billede-kort gunstig for indsigter til eHealth-udviklingsprocesser?

Form: Workshoppen skal udformes så den giver forældrene mulighed for at diskutere og validere de tre situationer af self-care, som tages op. Konkret får de en bunke med kort af dilemmaer, statements og billeder som de kan diskutere et af gangen.

Medbring: consent-formler, diktafoner, Ting til bordet: billeder fra mit feltarbejde, diskussionskort.

14.15-15.15

a. Introduktionskort: ”I denne bunke af kort findes forskellige statements og billeder, som trækkes og diskuteres ét af gangen. Der er 10 kort og der er sat omkring 6 min. af til diskussion af hvert kort, men nogle tager måske længere tid end andre. Forsøg så vidt muligt at nå igennem alle kort. Det ønskes, at jeres forskellige holdninger fremkommer ved diskussionerne – så byd endelig ind hvis I oplever tingene anderledes end andre. Kl. 15.15 laves en opsamling i plenum med de andre borde hvor bordene spørges til hvad I synes var spændende at diskutere. Nu: tag en kort runde hvor I introducerer jer selv for hinanden med navn, hvis forælder man er og yndlingsserie/film. Træk herefter et nyt kort."

1. <u>Hvilke "struggles" ser forældrende i børnenes hverdag med hæmofili og hvordan indgår materialitet til at fordre/udfordre self-care praksisser? Hvilke innovationer, der taler ind i etablerede praksisser, kunne forældrene forestille sig?</u>
    a. " Der er forskel på at være barn, ung og voksen med kronisk sygdom ift. ens egen rolle, læring og sociale liv."
    b. "Det er en udfordring for børn og unge med hæmofili at lære at håndtere deres sygdom. "Teknologi" kan hjælpe dem med at leve med og håndtere deres sygdom." (billede af imitation)
    c. "En bløder-app ville kunne løse konkrete udfordringer for mit barn og min familie og lære os noget."
2. <u>Hvad tænker forældrene om registreringer, data og deling med sundhedsprofessionelle ift. at få et overblik og lære om sygdommen? Hvordan forestiller de sig at det i praksis skulle foregår i deres hverdag? Hvilke nuværende praksisser skulle en digital løsning tale ind i? Hvordan skulle børnene inddrages i sådanne praksisser?</u>
    a. "Det er vigtigt at registrere symptomer og medicin i håndtering af hæmofili for børn og unge og dele data med hæmofilicentret." (billede af bløderapp)
    b. En bløder-app kan hjælpe børn og unge med hæmofili til at få overblik over deres sygdom men også over deres liv generelt gennem registrering af deres humør, søvn, aktivitet og energi." (billede af gigtapp)
    c. "De praksisser vi har for håndtering af sygdommen hjemme hos os har betydning for, hvordan vi ville bruge en bløder-app. Mit barn skulle fx inddrages i at registrere blødninger og medicin i appen."

3. Hvordan tænker forældrene at en holistisk eller en klinisk app ville relatere sig til deres norm om ”at sygdom ikke må fylde for meget”?
    d. ”Sygdom bør begrænses til at fylde så lidt som muligt. En bløder-app ville kunne få sygdom til at fylde mindre for mit barn og min familie og ville passe ind i praksisser vi allerede har.”
    e. ”Børn med hæmofili skal selv inddrages i hjemmebehandling fra 12-års-alderen, men først senere skal de koncentrere sig om relationen mellem blødninger og hvornår medicinen tages og blive uafhængige.”
4. Hvordan er denne metodologi omkring diskussioner af eksisterende praksisser, normer og nye teknologiske muligheder ved hjælp af statement/dilemma/billede-kort gunstig for indsigter til eHealth-udviklingsprocesser?
    f. ”Børn med hæmofili og deres familier skal inddrages i udviklingen af sygdoms-håndterings-teknologier.”

15.15-15.30

- Fælles snak i plenum om highlights af det der blev snakket om.
- Hvordan synes I workshoppen var?

Focus group guide youth panel

Til Ungepanelet forud for møde 16. maj

Oplæg til debat om hverdagen med sygdom og eHealth-løsninger 16. maj

Først og fremmest tak fordi jeg må komme til jeres møde i Ungepanelet! I er jo eksperterne i, hvordan det er at leve et liv med en sygdom, og jeg er meget taknemmelig over at få lov at høre jeres mening om eHealth-løsninger, og hvordan man bør blive behandlet som ungt menneske med en sygdom. Når vi mødes vil jeg fortælle lidt mere om mit projekt og svare på jeres spørgsmål. Jeg vil gerne optage det vi snakker om på lyd, så jeg kan huske, hvad der er blevet sagt. Jeg sletter lydfilen, når jeg har skrevet noter bagefter.

Projektet kort

Jeg er uddannet Tekno-antropolog og har de seneste år beskæftiget mig med telemedicin og eHealth. Jeg har gennem mit arbejde fundet ud af, at der mangler viden om, hvordan man laver eHealth til børn og unge, der lever med sygdom. Studier viser desuden at eHealth-løsninger til børn og unge ofte ikke rammer rigtigt.

Mit projekt undersøger hvordan sygdommen og behandling og alle mulige andre ting opfattes af børnene og de unge selv. Derudover undersøger jeg to udviklingsprojekter, der laver eHealth-løsninger (apps) til børn og unge med blødersygdom og børnegigt.

I sidste ende vil projektet give svar på, hvad man skal være særligt opmærksom på, når man udvikler eHealth-løsninger til børn og unge.

Fund indtil videre

Jeg har indtil videre besøgt og snakket med 15 børn og unge med blødersygdom og børnegigt. Her kan I se nogle af de ting jeg har opdaget indtil videre, som jeg gerne vil høre ungepanelets refleksioner om:

- Mange oplever nogle gange ikke at blive troet på
- Mange har svært ved at holde styr på hvad der sket gennem sygdomsforløbet
- Mange af de yngre børn leger at deres bamse/dukke har sygdommen og leger at de behandler den
- Mange prøver at få sygdommen til at fylde mindst muligt
- Nogle eksperimenterer selv med at håndtere sygdommen på andre måder; fx hvornår man tager medicin, gennem kost eller ved at distrahere sig selv i ubehagelige situationer
- Der er ofte rutiner og ritualer omkring dét at få medicin

Oplæg til debat

Du må gerne overveje følgende spørgsmål, som jeg vil stille som debatemner:

- Hvilke eksempler har I på teknologi, der spiller ind i hverdagen med en sygdom? (fx apps, kalender, sociale medier)
- Hvad betyder ”data”, ”selvmonitorering”, ”beslutningsstøtte” og ”empowerment” for jer?
- Hvilke taktikker har I fundet gennem jeres erfaringer med at leve med en sygdom? (fx måder at fortælle om sygdommen på, huske ting, snakke om følelser)
- Hvilke ting bør barnet/den unge selv tage ansvar for hvornår?
- Hvornår skal unge/børn under 18 have en løsning til sygdomshåndtering i hverdagen?

Jeg glæder mig til at møde jer!

Venlig hilsen

Claudia Bagge-Petersen

Informed consent information for participants

Informeret samtykke til deltagelse i forskningsprojekt eMinor – eHealth til mindreårige med kroniske sygdomme?

SAMTYKKEERKLÆRING

Projektet undersøger, hvordan børn og unge med en kronisk sygdom oplever udfordringer og taktikker for sygdomshåndtering i hverdagen.

Projektet har til formål at skabe viden om, hvorvidt og hvordan man kan udvikle eHealth-løsninger, der passer ind i og forbedrer hverdagen for børn og unge med kroniske sygdomme.

Projektet tager afsæt i to cases af sygdomsområder, nemlig hæmofili og gigt. Disse to sygdomscases er valgt, fordi eHealth-løsninger er på vej til netop disse sygdomsgrupper og inkluderer børn og unge i deres målgruppe. Metoden er en kvalitativ antropologisk undersøgelse af familiernes men især børnenes/de unges hverdagsliv med sygdom. Projektet skal i alt involvere omkring 16 børn/unge, der enten har gigt eller hæmofili og desuden undersøge de to udviklingsteams bag de kommende eHealth-løsninger.

Projektet varetages af Ph.d.-studerende Claudia Bagge-Petersen, ansat på Københavns Universitet på Afdeling for Sundhedstjenesteforskning. Forskningsprojektet er delvist finansieret af CACHET (Copenhagen Center for Health Technology) og Telemedicinsk Videncenter i Region H.

- Alle oplysninger er fortrolige og bliver anonymiseret. Dette betyder, at ingen personlig information, såsom dit navn, eller andre identificerbare informationer, vil fremgå af resultaterne af projektet, med mindre vi specifikt laver andre aftaler.
- Jeres deltagelse i dette projekt indbefatter uformelle møder med Claudia, hvor I snakker og måske laver noget aktivt; som fx går en tur, besøger din skole eller spiller et spil.
- Disse møder vil indebære, at Claudia tager noter, og indimellem billeder og lyd- eller videooptagelser, hvis I godkender det.
- Ydermere er der mulighed for, at vi sammen finder på nogle nye måder at ”snakke” om jeres hverdag på. Det kan fx være at I tager billeder imellem vores møder, eller at vi chatter (kun på sikre medier som WhatsApp eller SMS).
- Da Claudia ikke er sundhedsprofessionel, blander hun sig ikke I, hvordan I behandler sygdommen derhjemme.

- Projektet undersøger desuden, hvordan Danmarks Bløderforening, FNUG, udviklere og børneafdelingerne på Skejby og Rigshospitalet arbejder ift. den kommende bløder-app og gigt-app, men deler ikke personfølsomme oplysninger om jer med disse aktører.
- Forskningsprojektets resultater vil blive publiceret i akademiske tidsskrifter, i FNUG og Bløderforeningens medlemsblade og diskuteret ved konferencer og seminarer.
- Hvis I ønsker at blive informeret om fremtidige publikationer, kan I modtage en kopi. I så fald skal I give Claudia besked. Vær opmærksom på, at det kan tage flere år, før en publikation udgives.
- I har ret til at trække jeres deltagelse tilbage på ethvert tidspunkt.
- Projektet er anmeldt til og godkendt af Datatilsynet, som har fastsat nærmere vilkår til beskyttelse af deltageres privatliv.

Jeg er meget taknemmelig for jeres deltagelse, og I kan altid stille mig spørgsmål eller komme med bemærkninger på clba@sund.ku.dk eller på telefon +45 61682341

Venlig hilsen
Claudia Bagge-Petersen,
Ph.d.-studerende ved *Afdeling for Sundhedstjenesteforskning, Institut for Folkesundhedsvidenskab, Københavns Universitet*

INFORMERET SAMTYKKE

- Jeg er indforstået med formålet med forskningsprojektet og alle mine nuværende spørgsmål er besvaret.

- Jeg har læst og forstået information om forskningsprojektet i beskrivelsen *"Informeret samtykke til deltagelse i forskningsprojekt* eMinor – eHealth til mindreårige med kroniske sygdomme?"

- Jeg er indforstået med, at samtaler, observationsnotater og eventuelt foto- og optagelsesmateriale vil blive opbevaret fortroligt og citater bliver anonymiseret.

- Jeg forstår, at jeg har retten til at afbryde min deltagelse i forskningsprojektet på ethvert tidspunkt, uden at det får konsekvenser for mit behandlingsforløb.

- Jeg forstår, at jeg har ret til at anmode om at dele af samtaler og andet materiale ikke bruges, hvis jeg føler dette er nødvendigt.

- Jeg er indforstået med, at jeg beholder en kopi af denne samtykkeerklæring, og at jeg kan kontakte Claudia Bagge-Petersen (clba@sund.ku.dk /+45 61682341), hvis jeg ønsker at tilbagetrække mit samtykke eller ændre vores aftale.

Venligst skriv her, hvis du ønsker at tilføje nogle detaljer til denne samtykkeerklæring:

Jeg giver hermed min tilladelse

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Deltagers underskrift	Navn og dato
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Far eller mors underskrift	Navn og dato
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Forskers underskrift	Navn og dato

Article in The Danish Haemophilia Society

Danmarks
Bløderforening

Børn og unge med hæmofili udfører egenomsorg på deres egne måder

I 2017 deltog 16 børn og unge mellem 7 og 17 år med hæmofili eller børnegigt og deres familier i et Ph.d.projekt om, hvad de selv gør i hverdagshåndtering af kronisk sygdom. De har fortalt om deres hverdag og vist, hvordan de praktisk forsøger at håndtere problematikker på deres egen måde.

Af Ph.d.-studerende Claudia Bagge-Petersen, Københavns Universitet

At vokse op med en kronisk sygdom kan være opslidende for børn og deres familier. Forældre og sundhedsprofessionelle spiller en enorm rolle i håndtering af sygdommen. Der mangler dog opmærksomhed omkring det, børnene på eget initiativ gør i årene op til, at de kan varetage håndteringen selv. Ofte overses børnenes egne forsøg på håndtering af sygdommen og deres liv generelt, fordi det falder udenfor det, som vi normalt forstår som egenomsorg.

Stikkeangst, selv-behandling og at fremstå normale

Et af børnene i projektet er 11-årige Mathias (pseudonym), som har svær hæmofili. Han har oplevet stikkeangst, der var så slem, at han løb hjemmefra, når han fornemmede, at det var tid til behandling. Et andet problem for ham er at lære at behandle sig selv, fordi han altid selv ligger passivt på køkkenbordet, når faren giver ham faktor. En tredje problematik for Mathias er at være en helt normal dreng til fodboldtræning eller i skolen, når han nogle gange har smerter eller bliver nødt til at tage hjem for at få faktor. Disse problematikker gik igen blandt børn og unge i projektet. Det viste sig dog, at de selv gjorde en masse for at gøre det bedre.

Børn accepterer hjemmebehandling bedre, hvis de inddrages

Hjemmebehandling af børn med hæmofili kan være yderst stressende for hele familien. Forælderen som behandler, det kliniske udstyr og barnets krop som genstand for injektion er uvant i hjemmet. For børnene kan det være skræmmende, fordi de ikke har overblik over, hvad der skal ske. De er bange for smerten og kan ikke genkende sig selv i rollen som patient.

Familierne forsøger at etablere en klar rutine eller ”drejebog” for hjemmebehandlingen, hvor alt sker på samme måde hver gang. For Mathias var hjemmebehandling meget utrygt. Men der skete et skift for ham, da de fik en bedøvende creme, som kunne minimere smerten. Han besluttede at give hjemmebehandlingen en chance til, og det gav anledning til at ændre i ”drejebogen”. Mathias tog en mere aktiv rolle, idet han blev ansvarlig for at påføre cremen inden stikket. Han foreslog også nogle andre ændringer. Umiddelbart er det små ændringer, men fordi Mathias var med til at lave dem selv og fik ansvar, accepterede han hele proceduren bedre. Han fik indflydelse og kunne nu være stolt af sin aktive medvirken i kontrast til, da han passivt var genstand for behandling.

At skabe sin egen behandlerrolle gennem eksperimenterende leg

I Danmark ser vi gerne, at børn og unge tidligt tager ansvar og bliver selvstændige på en lang række punkter. Det kan være svært for børn og unge med hæmofili. Fordi symptomer og behandling er så komplekst, afhænger de af deres forældre i højere grad end jævnaldrende. Langt de fleste af børnene i projektet havde dog selv taget fat på at lære, hvordan de kunne blive mere selvstændige i sygdomshåndtering.

Nemlig gennem leg. I en meget tidlig alder havde de leget, at de behandlede andre, ofte deres bamser. Legene tillader, at børnene forlader rollen som behandlet og i stedet indtager rollen som

behandler. I den rigtige behandlingssituation kan de ikke få overblik over alle handlinger, da de har en mere passiv rolle. I legen imiterer de forældrenes eller klinikernes handlinger og undersøger processen. Når de bliver ældre, skal de kunne indtage både behandler og behandlet-rollen på én gang, og her kan de ikke kopiere den drejebog, de har sammen med forældrene. Der skal en ny drejebog til at behandle sig selv, og
legene er en hjælp til at begynde at se sig selv som selv-behandler.

Værdien i at være normal blandt jævnaldrende

For børnene og de unge i projektet hører deres symptomer og behandling til derhjemme. I skolen eller til fritidsaktiviteter er det vigtigt at optræde så normal som muligt. Det usynlige ved hæmofili eller børnegigt, gør det svært for jævnaldrende at acceptere den ekstra opmærksomhed, der gives til disse børn. Børnene og de unge kan blive mødt med mistro omkring oplevelsen af smerte og afholdelse fra bestemte aktiviteter. Mistroen og jalousien fra jævnaldrende over den ekstra opmærksomhed gør, at mange af børnene og de unge afholder sig fra at henvise til deres sygdom både offline og online, medmindre der er en god grund, som fx indlæggelse. Det vigtige at bemærke her er, at det for børnene i projektet ikke handler om, at de ikke ønsker omsorg og opmærksomhed. De vil bare ikke fremstå som nogen, der higer efter at få det!

Børn og unge som med-designere af deres hverdagshåndtering af sygdommen

Som vi kan se af eksemplerne går børn og unge i projektet op i tryg hjemmebehandling, at lære selv-behandling og at have et godt socialliv. De gør det bare på en måde, som kan være svær at få øje på med det voksne blik. Det er deres forsøg på at finde sig til rette med en kronisk sygdom. Denne viden om børnenes og de unges motivation for at have en rolle, de kan være stolte af, at eksperimentere og at kunne være normale blandt jævnaldrende kan bidrage til, at vi i fremtiden kan designe digitale løsninger, der støtter dem i at tage ejerskab over håndteringen og opnå deres egne mål. Hvordan en digital løsning ville kunne understøtte dette er næste undersøgelsespunkt i Ph.d.-projektet, som løber frem til august 2021.