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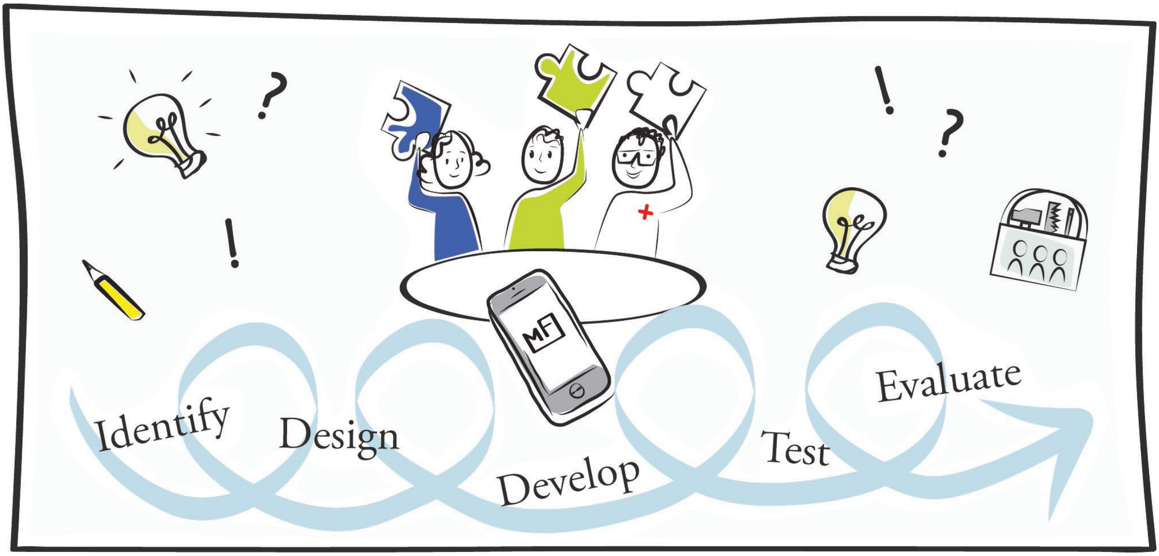

EXPLORING THE POSSIBILITIES OF SMARTPHONE-BASED YOUNG ADULT SCHIZOPHRENIA CARE

A PARTICIPATORY DESIGN STUDY

BY
MALENE TERP

DISSERTATION SUBMITTED 2019

AALBORG UNIVERSITY
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ENGLISH SUMMARY

Background and objectives

Research indicates that smartphone-based care has the potential to support individuals recently diagnosed with schizophrenia, to deal with their illness. Knowledge in the area, however, is sparse. This has motivated this thesis to:

I: Identify the needs of support in young adults recently diagnosed with schizophrenia; to design and develop a smartphone technology responsive to their needs; and to test the technology as an intervention in order to evaluate if and how it supports the needs of the young adults in the everyday management of living with the illness.

II: Investigate whether Participatory Design (PD) thinking and tools can enable young adults diagnosed with schizophrenia to participate and engage in the design of a smartphone technology to accommodate their needs of support.

The study was carried out in collaboration with young adults (18-36 years) with schizophrenia and healthcare providers (HCPs) from the Ambulatory for young adults with schizophrenia - OPUS, at Aalborg University Hospital, Denmark. The study was organized as a PD process and conducted on the basis of PD core principles. A combination of qualitative methods, user activities and the intervention itself were used to produce data. The approach to data analysis was hermeneutic.

Material and methods

Participant observations (45 hours) were conducted to construct an interview guide. The guide was used to explore the needs of support in young adults with a recent diagnosis of schizophrenia. Four woman and two men participated in the interviews.

Interview findings guided the subsequent design process in which the technology was developed. The design process was iterative, and was implemented using 10 co-design workshops. The process involved four young adults with schizophrenia, seven HCPs, five designers, a graphic recorder and an IT project manager.

The technology was pilot-tested for six months by two young adults and two HCPs from OPUS. After adjustment, it was implemented as part of the standard course of care at OPUS. The intervention period was 12 months. 27 young adults used the technology, and 13 evaluated its use and provided their perspectives on its usefulness. The evaluation was qualitative and conducted using in-depth interviews.

Data sources on the co-design process - workshop invitation, workshop descriptions and notes, SMS messages, emails, written reflection and group interview with the young adults - were analysed in order to investigate whether or not and how PD thinking and tools may have contributed to creating engagement and participation in the development of the technology. The analysis was guided by Wenger's Community of Practice theory.

Findings

- Interviews identified low levels of knowledge and high levels of uncertainties among the participants and a vast need of support to confidently self-manage the new life situation.

- From co-design workshops emerged an app with an affiliated website (MindFrame) that could be used to empower self-management of the new life situation by means of health monitoring, awareness and notification on changes in health, customized psychoeducation and strategies to stay in good health and medication management support.

- The intervention revealed that HCPs were somewhat reluctant to introduce the young adults to MindFrame. 20% (20/97) of the eligible participants were not asked by their HCP because the HCP had reservations. The intervention also revealed that the young adults had reservations about MindFrame. Only approximately 35% (27/77) of those invited to use it chose to do so. In addition the intervention revealed that prolonged use of MindFrame was hard to establish. 38% (5/13) of the sample who evaluated MindFrame terminated use within one month. Reasons provided for early termination included issues such as boredom, fatigue and problems quantifying the health.

- Evaluation interviews identified that MindFrame aided the participants to keep up their medication, to keep a step ahead of their illness, and to get appropriate help based on their needs (when it was used with the HCPs and consistently for more than a month). Yet, MindFrame could also fuel fear and worries of restraint and increase uncertainties in some participants about their mental health, thereby disempowering them from feeling certain and secure. This was observed in participants who had concerns even before starting its use and participants who generally and daily dealt with doubt and hesitation about their mental health state. Fears and uncertainties disappeared with use of the app in all but one participant who embellished his self-assessment scores to remain in control.

- Analysis of the co-design process identified that PD thinking and tools aided the construction of an engaging room that enabled the young adult participants to become strong collaborators in the design of MindFrame. The room had the threefold characteristics of a community of practice and the special qualities of transparency, flexibility, security and informality. The room was not only efficient to develop MindFrame, it was also efficient in aiding the participants to discover and realize their own capabilities, competences and skills. In that sense, it worked as an engine for learning.

Conclusion

The study concludes that:

- Smartphone-based care has the potential to support young adults recently diagnosed with schizophrenia to confidently manage everyday living with the illness. This, however, requires that they monitor their mental health for more than a month and use the technology closely with their HCP.

- Smartphone-based care may disempower some young adults recently diagnosed with schizophrenia from feeling certain and secure. Therefore, on going evaluation of how the care is affecting the individual, is required.

- Smartphone-based care has it restrictions and does not appeal to everyone. Studying young adults who have recently been diagnosed with schizophrenia, but who opt out of using technology as a part of their care when it is offered, could help explain this.

- HCPs are crucial for the future of smartphone-based young adult schizophrenia care. Therefore, future research should look into their reservations.

- PD thinking and tools can inspire and support participation and engagement in the development of smartphone-based care with young adults with schizophrenia, given that the environment in which PD unfolds is transparent, flexible, safe and informal. In addition, PD can strengthen the perception of value and worth, thereby promoting personal power. Future research is highly recommended to look into the potential of PD principles and thinking to support young adults diagnosed with schizophrenia on their journey towards mental health recovery.

DANSK RESUME

Baggrund og formål

Forskning indikerer, at smartphone-baseret pleje har potentialet til at støtte mennesker med ny diagnosticeret skizofreni til at håndtere deres sygdom. Viden på området er imidlertid sparsom. Dette har motiveret denne afhandling til:

I: at identificere behovet for støtte hos unge voksne med nyligt diagnosticeret skizofreni; at designe og udvikle en smartphone teknologi der understøtter de unges behov og at teste teknologien som en intervention for at vurdere, om og hvordan den hjælper de unge i håndteringen af det daglige liv med sygdommen.

II: at undersøge om Participatory Design (PD) tænkning og værktøjer gør det muligt at involvere og engagere unge voksne med skizofreni i at designe en smartphone teknologi, der imødekommer deres behov for støtte.

Studiet blev gennemført i samarbejde med unge voksne (18-36 år) med skizofreni og sundhedsprofessionelle fra Ambulatorium for unge med skizofreni - OPUS, ved Aalborg Universitetshospital. Studiet var organiseret som en PD proces og blev udført med afsæt i PD principper. En kombination af kvalitative metoder, brugeraktiviteter og intervention blev anvendt til at producere data. Tilgangen til dataanalyse var hermeneutisk.

Materialer og metoder

De unges behov for støtte blev identificeret ved hjælp af individuelle interviews. Interviewene var kvalitative og blev gennemført ved hjælp af en spørgeguide udviklet på baggrund af 45 timers deltagerobservation. Fire kvinder og to mænd deltog i interviewene.

Interviewene var retningsgivende for den efterfølgende design proces, hvor teknologien blev udviklet. Design processen var iterativ, og blev gennemført ved hjælp af 10 design workshops med deltagelse af fire unge med skizofreni, syv sundhedsprofessionelle, fem designere, en grafisk recorder og en IT-projektleder.

Teknologien blev pilot-testet i seks måneder af to unge og to sundhedsprofessionelle fra OPUS. Efter tilretning blev den implementeret som en del af standardbehandlingen i OPUS. Interventionsperioden var 12 måneder. 27 unge afprøvede teknologien. De unge blev efterfølgende inviteret til at evaluere teknologien, 13 deltog. Evalueringen var kvalitativ og blev gennemført ved hjælp af individuelle interviews.

Datakilder omkring design processen – workshop invitation, beskrivelser og noter, sms-beskeder, e-mails, skriftlig refleksion og gruppe interview med de unge -blev analyseret med henblik på at undersøge hvorvidt og hvordan PD tænkning og redskaber bidrog til at skabe engagement og deltagelse hos de unge. Analysen blev guidet af Wengers teori om praksisfællesskaber.

Studiets fund

- Interviewene identificerede lav grad af viden og høj grad af usikkerhed blandt de unge og et udpræget behov for støtte for trygt selv at kunne håndtere den nye livssituation.

- Ud af design processen fremvoksede en app tilknyttet en hjemmeside. Teknologien hed MindFrame og var udviklet til at empower håndteringen af det daglige liv med skizofreni ved hjæp af: selv-monitorering, identificering af tidlige advarselstegn, notifikationer om forværring, individualseret psykoedukation, strategier til at mestre sygdommen og medicin overblik.

- Interventionen viste, at de sundhedsprofessionelle i OPUS var tilbageholdende med at introducere de unge til MindFrame. 20% (20/97) af mulige MindFrame brugere blev ikke introduceret til muligheden. Interventionen viste, at de unge også var tilbageholdende omkring brugen af MindFrame. Kun ca. 35% (27/77) af dem der blev introducere til muligheden, valgte at bruge den. Hertil kom, at 38% (5/13) af dem der brugte MindFrame valgte at afslutte brugen indenfor den første måned. Dette var begrundet i bl.a. udtrætning, kedsomhed og problemer med at kvantificere den psykiske tilstand.

- Evalueringen viste, at når MindFrame blev brugt i mere end en måned og i tæt samarbejde med de sundhedsprofessionelle, så var den en hjælp til at holde styr på medicin, en hjælp til at være et skridt foran sygdommen og en hjælp til at få den hjælp der matchede ens behov. Evalueringen viste også, at MindFrame kunne øge frygt og bekymringer for tvang og øge usikkerheden om den psykiske tilstand. Dette blev observeret hos unge, der var særligt usikre på deres psykiske tilstand og unge, der havde været bekymrede for at bruge teknologien, før den blev taget i anvendelse. Frygt og usikkerhed forsvandt med brugen af teknologien hos alle de unge, med undtagelse af en. Denne unge 'pyntede' på sin psykiske tilstand for at forblive i kontrol.

- Analyse af design processen viste, at PD tænkning og værktøjer var en hjælp til at skabe et frugtbart miljø, der muliggjorde for de unge at bleve stærke samarbejdspartnere i udviklingen af MindFrame. Miljøet materialiserede sig som et praksisfællesskab, der var gennemsigtigt, fleksibelt, trygt og uformelt. Praksisfællesskabet engagerede de unge, men havde også funktion som en 'motor' for læring hvor de unge gennem deltagelse fik øje på egne evner, kompetencer og færdigheder.

Konklusion

Studiet konkluderer, at:

- Smartphone-baseret pleje er en mulige måde at støtte unge voksne med ny diagnosticeret skizofreni til at håndtere det daglige liv med sygdommen. Dette fordrer imidlertid, at de unge monitorerer deres psykiske tilstand i mere end en måned og anvender teknologien sammen med deres behandler.

- Smartphone-baseret pleje kan skabe utryghed og frygt hos nogle unge voksne med skizofreni. Derfor, skal plejeformen løbende evalueres.

- Smartphone-baseret pleje har sine begænsninger og appellerer ikke til alle. Yderligere forskning blandt gruppen af unge der fravælger at bruge en teknologi som en del af deres behandlingsforløb, kan være med til at etablere dette.

- Sundhedsprofessionelle har afgørende betydning for fremtiden af smartphone-baseret pleje blandt unge voksne med ny diagnosticeret skizofreni. Derfor kan fremtidig forskning med fordel se på deres tilbageholdenhed.

- PD tænkning og værktøjer kan inspirere og støtte deltagelse og engagement i udviklingen af smartphone-baseret pleje med unge voksne med skizofreni, givet at miljøet hvor PD udfolder sig, er transparent, fleksibelt, sikkert og uformelt.

- PD er ikke kun effektiv til at skabe engagement i udviklingen af en teknologi til smartphone-baseret pleje, men også til at styrke de unges opfattelse af deres værd og værdi. Fremtidig forskning kan med fordel se nærmere på hvordan PD principper og tænkning kan anvendes i processen med at styrke unge med skizofreni i deres personlige proces med at komme sig.

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Malene Terp
Risskov, 2019

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LIST OF PAPERS

The present thesis is based on three papers. The papers will be referred to in the thesis by their roman numerical.

Paper I
Terp M, D. Bjørnes C, Jørgensen R, Mainz J, Laursen BS. Collaborating with Young Adults Diagnosed with Schizophrenia: A Participatory Design Study to Shape the Healthcare System. *Open J Nurs* 2017;07:743–758.

Paper II
Terp M, Jørgensen R, Laursen BS, Mainz J, Bjørnes CD. A Smartphone App to Foster Power in the Everyday Management of Living With Schizophrenia: Qualitative Analysis of Young Adults' Perspectives. *JMIR Ment Heal* 2018;5(4):e10157.

Paper III
Terp M, Laursen BS, Jørgensen R, Mainz J, Bjørnes CD. A room for design: Through participatory design young adults with schizophrenia become strong collaborators. *Int J Ment Health Nurs* 2016;25:496–506.

In addition to the papers two short films were produced to disseminate findings. The films were produced in layman terms to reach a broader audience. The films were co-created with a study participant. The films are available on YouTube [1,2].

LIST OF FIGURES, TABLES, ABBREVIATIONS AND DEFINITIONS

Figures

Tables

Abbreviations

Abbreviation	Full word
App	Application
Co-design	Collaborative design
COP	Community of practice
EWS	Early warning signs
HCP	Healthcare provider
mHealth	Mobile health
PD	Participatory design
RCT	Randomized controlled trial
UIM	User innovation management

Definitions

Concept	Definition
Care	The provision of what is necessary for the health, welfare, maintenance, and protection of someone or something [3].
Empowerment	A process in which someone is made stronger and more confident in controlling their lives [4].
Empower	To make (someone) stronger and more confident or to give (someone) the authority or power to do something [5].
mHealth	Short for mobile health. It is a medical and public health practice supported by mobile devises, such as mobile phones, patient monitoring devices, personal digital assistants (PDA's) and other wireless devices [6]. In this research mHealth relates to smartphones.
Participatory Design	A research methodology and design approach [7]. The methodology is further explained in chapter 4.
Power	The ability or capacity to do something or act in a particular way [3].
Recently diagnosed	The first two years after the diagnosis.
Recovery	A process of change through which an individual achieves improved health, wellness and quality of life [8,9].
Self-care	The practice of taking action to preserve or improve one's own health [3].
Self-efficacy	Beliefs in one's capabilities to mobilize the motivation, cognitive resources, and courses of action needed to meet given situational demands [10].
Schizophrenia	A severe mental illness [11] characterized by alterations in thinking, behaviour, perception and the sense of self [12].
Smartphone	A mobile phone having a touchscreen interface, Internet access, and an operating system capable of running downloaded apps [3].
Smartphone app	A native software application downloaded directly onto the phone.
Smartphone-based care	Use of the smartphone to provide what is necessary for the health, welfare, maintenance, and protection of somebody where and when it is needed.
Young adults with schizophrenia	Individuals between the ages of 18-36 years diagnosed with schizophrenia per the structured interview of ICD-10.

CHAPTER 1. INTRODUCTION AND BACKGROUND

In this chapter the study is introduced. First the motivation for the study is stated, then the literature is reviewed, and on this basis the study rationale is claimed.

1.1. Motivation for the study

Schizophrenia is a severe [13,14] and distressing mental illness [15] that affects approximately 1% of the population globally [16]. The illness, which typically sets off in young adulthood [17], represents a new life situation - a transition in health [18], which needs to be managed around the clock.

Supporting management efforts in individuals with a recent diagnosis of schizophrenia involves collaboratively helping them acquire the skills and confidence to efficiently manage their new life-situation in the context of their daily lives. A common problem, however is, that many young adults skip their ambulant visits in the mental health clinic [19,20], leaving them with only little knowledge and skill power to react timely to the illness related challenges that they face. This causes a serious threat to their current and future health and quality of life [21,22].

A means to aid young adults diagnosed with schizophrenia to confidently manage their new life situation could be to provide 'care at a distance' [23] by the means of smartphone technology. The pervasive nature of the smartphone allows for healthcare to move beyond the confines of the physical clinic [24,25] and into the home and even pocket [26] of the individual to aid support regardless of time and place [24,27,28]. Smartphone ownership is particularly high in young adults diagnosed with schizophrenia [29] and research has established that they are amenable to using a variety of technologies as part of their care [30–33]. This includes the use of technology for information, reminders and decision-making tools pertaining to treatment and recovery [29]. Given young adults recently diagnosed with schizophrenia are willing and able to use smartphone technology to support their everyday management of living with the illness, disengagement from consultations in the clinic could be less of a threat to their recovery. This has motivated this thesis to explore whether smartphone-based care is a viable solution to support the everyday management of living with recently diagnosed schizophrenia.

1.2. Literature review

To obtain an understanding of the existing research on the usefulness and impact of smartphone technology in the care for young adults with schizophrenia, a literature review of the peer-reviewed literature was conducted when the research process initiated in spring 2013. Since then, the literature has been continually reviewed. Yet, the knowledge gained from the initial literature review provided the starting point for the research process and was crucial for the choice of research approach. Therefore, the following section descibes the first review process and its findings. **Appendix A** provides an updated search per March 2018. Studies from the updated search are included in the papers and the discussion section.

Criteria´s and bibliographic databases

Studies for the review were required to meet the following criteria; (1) the study includes young adults (18-36 years of age) with a diagnosis of schizophrenia; (2) the study reports on the use, usefulness or impact of a smartphone technology as part of schizophrenia care; (3) the study is peer-rviewed and published in English or Nordic language.

CINAHL, PubMed, Health Technology Assessment Database (HTAD) and PsycInfo via Proquest were systematically searched. MeSH and equivalent terms were used when applicable. To cover the age-range of 18-36 years, filters were set. The search strategy employed was as follows:

Schizophrenia **OR** Schizophren* **AND** Cell Phone **OR** smartphone* **OR** mobile applications **OR** mobile app* **OR** "mobile intervention" **OR** mobile health* **OR** "mHealth" **OR** "mobile mental health"

Filters: Young adults (19-24 years). Adults (19-44 years)

Once the key articles, relevant to the review, had been identified, they were searched in Web of Science and Scopus (citation databases) and their reference lists were scrutinized for further studies. Author searches [34] were carried out to identify publications not found in the electronic search, and to spot work in progress. A flow chart of the search results is provided in **Figure 1.**

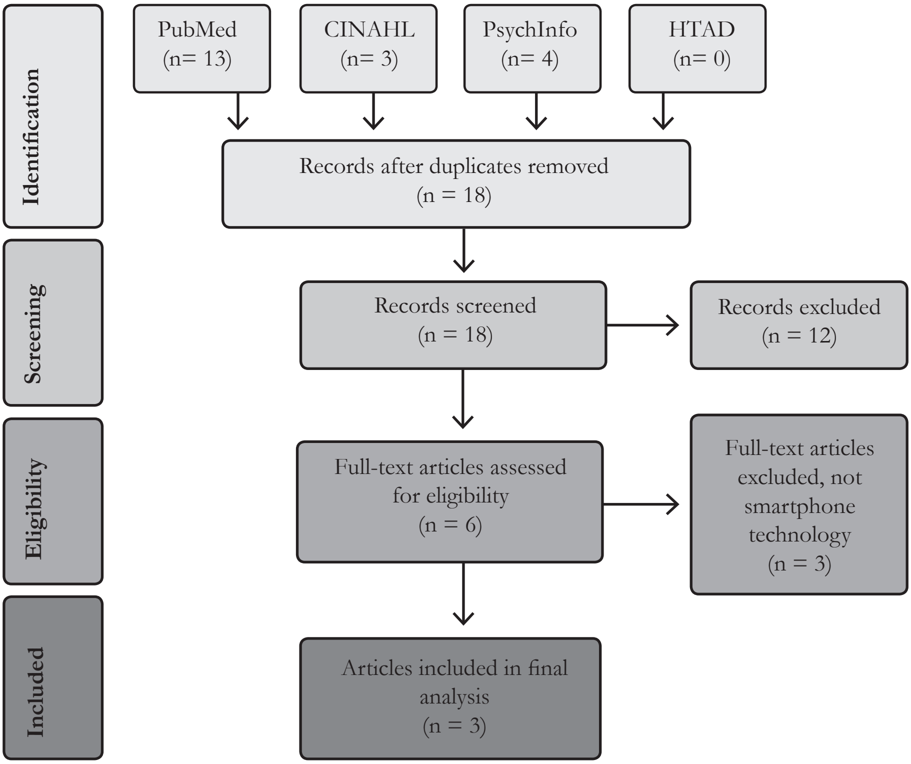


Figure 1. Flow chart of the search results

1.3. Main findings of the review

The overall characteristics of the included studies are given in **Table 1.** The studies reported on the use, usefulnesss and impact of a native smartphone application (app) designed to monitor psychotic symptoms in real-time. The studies were conducted in the UK and included individuals between the ages of 18-49 years with psychosis at varying severity. One study was a feasibilty study [35], the others were a randomized repeated measure cross over design study [36] and an interview study [15], respectively. The sample in the randomized repeated measure cross over design study and the interview study were the same. Two studies used a quantitative design [35,36]. One study used a qualitative design [15].

Table 1. Characteriscs of the included studies

SAuthor, year, and country	Aim(s)	Design	Methods
Palmier-Claus et al., 2012, United Kingdom [35]	To assess the feasibility and validity of ambulatory self-report of psychotic symptoms using a smartphone software application.	Quantitative	Individuals with psychosis were prompted at six pseudo-random times, each day, for seven days to assess key psychotic symptoms using the ClinTouch app. They were prospectively recruited into 3 groups: acute, remitted and ultra high risk 'prodromal'. Recruitment continued until each group contained 12 subjects who had managed to complete at least 33% (defined as compliance) of the 42 data points possible. Feasibly and validity was assessed using clinician rated symptom scores and self-reported health data.
Ainsworth et al., 2013, United Kingdom [36]	To compare two different delivery modalities of the same diagnostic assessment for individuals with non-affective psychosis – a native smartphone app employing a graphical touch user interface against an SMS text-only implementation	Quantitative	Using a randomized repeated measure cross over design a sample of community-based individuals with currently treated schizophrenia (n=22) or schizoaffective disorder (n=2) were randomly allocated to completing 6 consecutive days of assesments (4 sets of questions per day at pseudo random times) with an app

			(ClinTouch) or an SMS text-only implementation. To reduce carry over effects a seven days rest period were held between using modality 1 and modality 2. Quantitative feedback questionnairs were administred at the end of each period of sampling to assess the acceptability and feasibility of the two delivery modalties.
Palmier-Claus et al., 2013, United Kingdom [15]	To understand patient's perceptions of mobile phone based assessment systems and how they may be implemented into everyday routine and clinical practice.	Qualitative	Using qualitative interviews a sample of 24 individuals with schizophrenia (see above) were interviewed about perceived use of mobile based assesement and its use in eveyday routine and clinical practice.

Smartphone use in schizophrenia care

The included studies reported on the use of a smartphone app (ClinTouch) to monitor psychotic symptoms in real-time [35,36]. The app was used with individuals across different ages, severities and stages of schizophrenia. Palmier-Claus et al., found, that study participants were willing to assess their health using the app and capable of delivering valid and clinically meaningful data. However, it was identified that six out of eight participants with acutely psychotic symptoms, were non-adherent to the assessment procedure [35]. Severe symptomology, thus, impacted use of the app.

The use of the app was compared to an SMS text-only implementation. Ainsworth et al., identified that significantly more data points were completed in the app, and the app was nearly five times faster to use. There were no significant differences in the participant's quantitative feedback for the two delivery modalities; yet, most (67%; n=16) preferred the app and found it easier to use (71%; n=16) [36].

Smartphone usefulness in schizophrenia care

Mean quantitative feedback scores showed generally positive appraisals of the app. Yet, the appraisals varied considerably between individuals. While some felt that the technology could help them, others were more skeptical about its advantages [36]. One in three reported that they were willing to complete mobile phone assessments for five weeks or longer [36]. For most of the participants the personal value of the app in its current form, thus, was not considered to be strong enough to motivate long-term adoption.

In response to completing assessments some got more preoccupied with their thoughts and were reminded of past periods of acute illness. Others felt that the assessments led to unfavourable comparisons between their desired and their actual mental health state, and drew attention to the high frequency of their psychotic symptoms and thoughts about suicide. Yet others, felt that the increased levels of retrospection had a positive effects in terms of showing them how much progress they had made since they were last acutely unwell [15]. Thus, the perceived usefulness of the app was somewhat mixed.

Perceived impact of smartphone use in schizophrenia care

The perceived benefits of the app were mainly seen as being in favour of the HCPs. The qualitative accounts on the use and usefulness of the app showed that the participants often perceived the app as a tool enabling their HCPs to gain insights into their mental health state, as well as for the HCPs to foster better communication and to initiate effective intervention [15].

Although many acknowledged that greater levels of data could be helpful to their HCPs, most felt that the app was a potential threat to existing care. Many of the participants perceived the app as being impersonal and unable to address their everyday problems and stressed that its use could not be a substitute for face-to-face consultations [15].

Although many believed that there were benefits of integrating smartphone technology into their clinical case management, the participants did not think it would be relevant to their personal situation. The reasons for this varied. Whilst some thought themselves to be no longer mentally unwell, others felt that their existing contact with their HCPs made monitoring redundant. Some emphasised that during periods of stability in symptoms or remission many of the advantages of mobile assessment were lost, making the assessment procedure 'overkill' [15].

Limitations of the review

The viability of using a smartphone technology to support the everyday management of living with recently diagnosed schizophrenia, was hard to establish due to a number of issues.

First, the studies reported on one smartphone technolgy only. This technology was used for symptom monitoring, and as such, this was the only feature explored as part of the ambulant care regime. The broader use of a smartphone technology e.g. to allow for young adults diagnosed with schizophrenia to access educational materials to better self-manage their everyday problems or to increase collaborative management of their condition, is unclear.

Second, the samples in the studies ranged in 1) age, 2) living arrangement and 3) stage and severity of schizophrenia. The inhomogeneous samples and lack of subsample analyses makes it hard to determine to what extend the findings apply to community dwelling young adults recently diagnosed with schizophrenia.

Third, the specific ages for the subset of 'acute' participants' non-adherent to the smartphone technology procedure were not provided. Whether a smartphone technology can be used in recently diagnosed young adults, who often experience severe symptomatology [21] thus, is unclear.

Fourth, the studies report on feasibility based on six [36] and seven [35] days of app use. The short intervention periods make it hard to determine the viability of using an app over the course of time in the everyday management of living with schizophrenia.

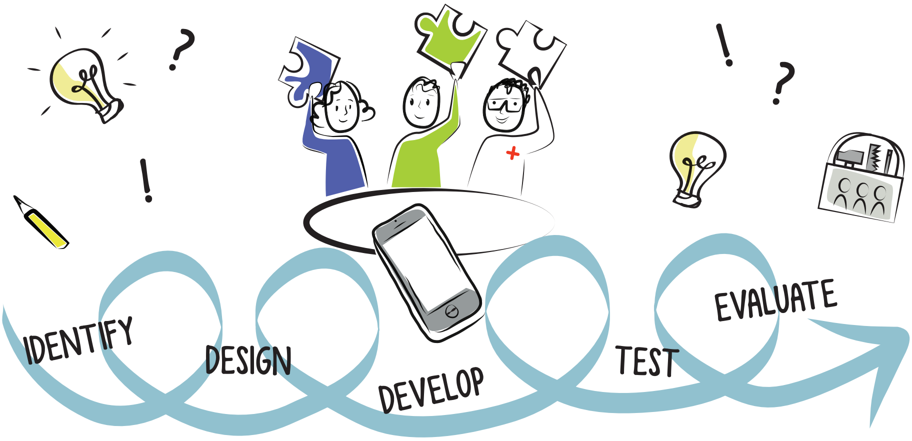
1.4. Rationale for the study

In sum, the review indicated that smartphone-based care is feasible among young adults with a recent diagnosis of schizophrenia, given the technology is an add-on to face-to-face care, able to address everyday problems and helps to accommodate these problems. Yet, at the same time the review indicated that severe symptomatology, which is common in the earliest phases of schizophrenia, might impact the acceptability of use. This inconclusive and fuzzy picture demonstrates a knowledge gap and provides the rationale for an explorative study investigating: 1) how a smartphone technology should be designed to be of relevance in the everyday life context of young adults diagnosed with schzophrenia and 2) how such a technology is used, in order to understand its perceived benefits and restrictions.

The review showed that the participants perceived the technology in favour of the HCPs, rather than in their own favour. This emphasises the relevance of engaging individuals with schizophrenia in designing the technology to make sure that it´s responsive to their needs. Participatory design (PD), which is also known as co-design [37,38], is a collection of practices, principles and applications involved in the design for, rather than on the basis of its users [7]. PD has been widely documented in non-psychiatric populations as an emancipatory approach to establish engagement in the design of technologies [39–42]. The usefulness of PD thinking and tools within the field of mental health care development is unknown. Yet, since user-involvement is at the heart of recommendations for a more sustainable mental healthcare system [43] and New Public Governance is a prevailing management paradigm in the public sector [44] its potential is interesting to establish.

CHAPTER 2. AIMS AND OBJECTIVES

In this chapter the aims of the study are stated and the objectives governing the aims are provided. At the end of the chapter the clinical and methodological contributions of the study are claimed.



2.1. Aims of the study

On the basis of the literature review, the aim of this study was twofold. First, it was to explore whether smartphone-based care could be a viable solution to support young adults recently diagnosed with schizophrenia in the everyday management of living with the illness. Second, it was to investigate the contribution of participatory design thinking and tools to engage young adults with schizophrenia in the design of a technology for smartphone-based care.

2.2. Objectives of the study

The objectives governing the aims are outlined below.

I: To identify the needs of support in young adults recently diagnosed with schizophrenia; to design and develop a smartphone technology responsive to their needs; and to test the technology as an intervention in order to evaluate if and how it supports the needs of the young adults in the everyday management of living with the illness.

II: To investigate whether participatory design thinking and tools can enable young adults diagnosed with schizophrenia to participate and engage in the design of a smartphone technology to accommodate their needs of support.

2.3. Contributions of the study

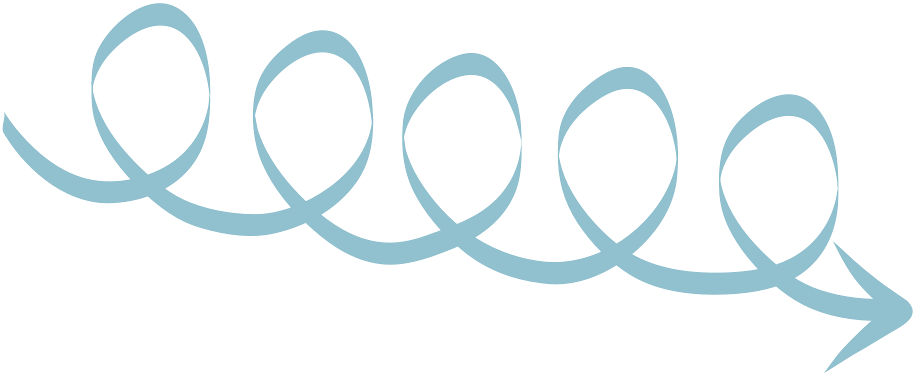
The study stems from an ambition to explore how smartphone technology may be used to support the everyday management of living with recently diagnosed schizophrenia.

On a clinical level, the study adds to the sparse research base on the usefulness of smartphone technolgy as part of young adult schizophrenia care. These insights may contribute to increased understandings of the promises of smartphone-based schizophrenia care and uncover the ‘red flags’ related to integration of smartphone technology into the ambulant care regime. Insights that may well guide future implementation of smartphone-based mental health care among different diagnostic groups.

On a methodological level the study can contribute knowledge on PD thinking and tools to engage young adults diagnosed with schizophrenia as co-designers of smartphone-based care responsive to their needs and preferences of support. Such knowledge may benefit future projects by indicating how to design sustainable care solutions with, rather than for, individuals with mental health issues.

CHAPTER 3. PHILOSOPHICAL PERSPECTIVE

In this chapter the philosophical underpinning of the study is delineated. First, key aspects of the philosophical perspective are shared. Then, reflections on how the choice of perspective has impacted the research process are provided. The chapter ends with a brief summary.



3.1. Hermeneutics

The philosophical underpinning of the study was hermeneutics. Hermeneutics is a philosophical scientific paradigm, which regards the theory and practice of interpretation [45]. A central, decisive figure of twentieth century interpretative hermeneutics is the German philosopher, Hans-Georg Gadamer (Gadamer). In this study, key aspects of Gadamer´s hermeneutic thinking provided the theoretical basis for interpretation, understanding and knowledge creation. Following, the key aspects are outlined, and their application in the study is summarized.

Hermeneutical circle

A grounding basis for hermeneutics is the hermeneutic circle [46]. The key insight upon which the hermeneutic circle is based is the insight that meaning is holistic. This is built on the perception that the whole is more than the sum of its parts [47].

According to Gadamer meaning emerges through a dialogue or hermeneutical conversation between text and the inquirer [47]. This conversation is open and dialogical in its nature, and allows one to return to the object of inquiry over and over again, each time with an increased understanding and a more complete interpretive account [45]. The hermeneutic conversation is key to understanding, as nothing that needs interpretation can be understood at once [47].

As a researcher, one will never know for sure when the 'perfect interpretation' has been reached, as there are always more contexts to apply to the problem. It is always possible to go around once more in the hermeneutic circle, and every time that is done, it may turn out that the previous interpretation was wrong, or at least inaccurate. Therfore, while applying the hermeneutic circle brings the researcher closer to the 'perfect interpretation,' one can never know for sure when he or she has arrived there. Hence, in theory, the process of interpretation can move on in infinity [48]. In practice, this is neither possible nor desirable, which is why the hermeneutic circle in this study ended when interpretations free from logical contradictions had been reached. This was the case when interviews were analysed, but also in the iterative process of innovating the technology.

Pre-understanding

According to Gadamer, all knowledge is based on an understanding that is expanded and articulated in an interpretation of what we already know. This means, that when we form part of an understanding process, we bring our pre-understanding of everything we know and think about a subject matter, into that process [46]. The pre-understanding, thus, is immanent, inevitable and indispensable.

An important part of the pre-understanding is prejudices – or pre-judices. Gadamer emphasise how pre-judices help us to better see and understand what is at stake. Hence, pre-judices are positively connoted, and not something that should be overcome [47]. This underlines that when hermeneutic thinking is applied in a PD setting, the researcher should not strive to put pre-understanding and prejudices on the subject matter under investigation into brackets, as suggested in Phenomenology, the school of thought in which hermeneutics is rooted [49]. The researcher forms part of the interpretative process and must use the pre-understanding as a tool to establish the hermeneutic conversation with the text and be receptive for what the text communicates. This, however, requires that the researcher be aware of what he or she brings into the understanding process and that he or she challenges the prejudices by putting them into play. Full knowledge about one's personal pre-understanding can never be obtained, as we are one with it. We will never be able to put into words all we know, since part of our knowledge is tacit. Yet, awareness can take us some of the way [46].

Situation

The basis for understanding in Gadamer´s hermeneutics is 'situation'. Situation is the context in which we are embedded [47]. Gadamer does not define the concept of situation precisely, but discusses the historical aspect of a situation [46]. Essentially, we have a history and an understanding of the world even before we begin to think about it, which directs and determines our understanding.

The situation has implications for the researcher (the subject) and for the subject matter under investigation (the object). One example of an implication is that participants in a study need to be understood as part of the context in which they are embedded. This requires that their perceptions must be interpreted in conjunction with interpretation of the context [46]. Another example of an implication is that the researcher´s understanding always arises from a particular situation, hence interpretations are neither random nor arbitrary [46]. This implication requires that the researcher carefully pays attention to the historic context her or she is embedded in to discover potential blind spots.

Horizon and fusion of horizons

Gadamer´s concept of situation is closely linked to the concept of horizon. Where situation is expressed as the stance from where one sees, horizon is expressed as how far one can see from that stance [46]. Horizon, thus, is the width of view from a particular viewpoint.

Understanding occurs when two horizons merge [47]. Merging, or fusion of horizons as Gadamer calls it, is a process in which individuals gain a better picture of what lies beyond their own horizon, by putting themselves in the other´s place. This does not involve subordinating oneself to the other, leaving the pre-understanding behind, or reproducing the other´s understanding. Rather, it involves producing 'something third,' that is on the 'other side' of oneself and the other [46], by putting one's pre-judices into play. In a research setting this requires that the researcher is open to the view of the other.

3.2. A hermeneutic perspective

The choice of hermeneutics as the philosophical perspective underpinning the study is important for the research process in a number of ways. The following section summarises how the perspective has impacted this study.

The hermeneutical perspective implies that the researcher is an active part in the process of generating knowledge. Consequently, I refer to myself as a subject throughout the thesis, rather than objectifying myself as ‘the researcher’.

As a researcher within the hermeneutic paradigm, awareness on my pre-understandings and prejudices, were important to establish to bring into consciousness how I impacted the research process. To this end, reflexive dialogue was used. The dialogue was established in two different forms: 1) as an unstructured interview between a fellow PhD student and me, and; 2) as conversations between my supervisors and me. The interview was conducted in the early phase of the research process to uncover my blind spots, whereas reflexive conversations were continuously applied in the research process to stay humble towards things ‘still not understood’ and to stimulate the movement of my horizon.

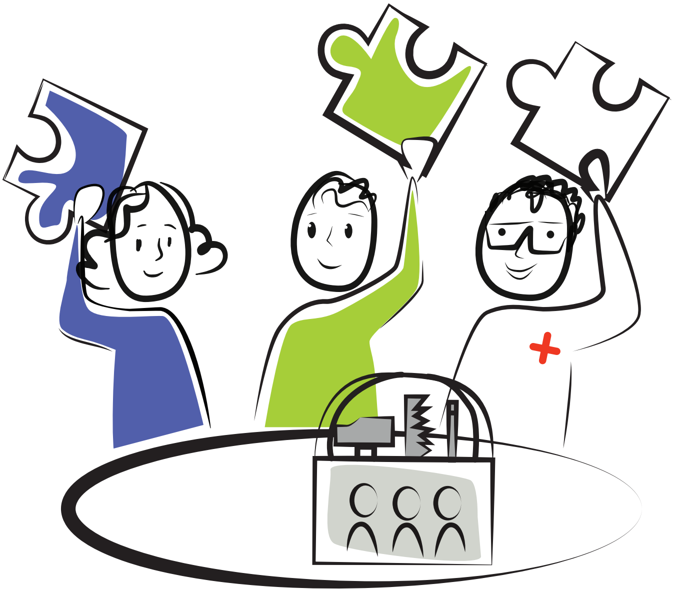
Methodologically, the hermeneutical perspective impacted the design and execution of the study. One example is that literature was iteratively searched, read and re-read throughout the research process as my horizon of understanding moved. Another example is that qualitative methods grounded in conversations (interviews) and design actions (co-design workshops) were chosen to generate new perspectives and insights based on the perception of understanding as something that may occur through mutual interaction. Yet, another example is, that context based actions (participant observations) were chosen to get a grasp of what mattered most to the young adults, in order to develop an interview guide to address their needs and preferences for support.

3.3. Summary

The philosophical underpinning of the research was hermeneutics including the concepts of the hermeneutical circle, pre-understanding, situation, horizon and fusion of horizons as outlined by Gadamer.

CHAPTER 4. PARTICIPATORY DESIGN APPROACH

In this chapter the approach to the study is described. First, the rationale for the approach is claimed. Next, the core principles driving the approach are described. Then, planning and management of the approach is outlined. At the end of the chapter the approach is summarized.



4.1. Participatory design

The study was conducted using a participatory design (PD) approach. The rationale for using a PD approach was grounded in research showing that engagement of end-users in design projects fosters better designs [50–52] and ultimately better outcomes [53].

4.2. Participatory design core principles

The choice of a PD approach meant that the research was guided by PD core principles. Following the core principles are outlined and the application of the principles in the study are briefly described.

Alternative visions for Technologies

PD is engaged with generating alternative visions for technology in order to use technologies for improvements and developments [50,54]. As evidenced in the background section, a vision of using the smartphone to improve the care for young adults with a recent diagnosis of schizophrenia provided the foundation of the study.

Equalizing power relations

PD originated as part of the 1960s and 70s political, social and civil rights movement in Europe as an action research approach to strengthen co-determination of workers at their workplaces [51,55–57]. The democratic and emancipatory belief governing PD was that those who would be affected by the changes from implementing communication and information technologies, should, as a basic human right, have the opportunity to influence the design of those technologies, and the practices that involved their use [52]. A grounding notion of PD today is, that users of a technology should have a voice when innovating a design [50].

Specific for PD is that users should be given voice as active partners [38,58,59] or as co-designers [60], rather than as informants through interviews, focus groups and other one-way techniques in a process that is otherwise controlled by designers and researchers [50,52]. The perception of participation in PD, thus, is contrary to the mindset of other design practices, e.g. user-centred design, where end-users of a design are relegated to study objects and recipients of the designed object [61,62]. Equalization of power relations in this study was sought through a research design where young adults with schizophrenia were given a say from the initial phase where needs were explored and prototypes made, to the final phase where the design was implemented and used as part of the care regime.

Democratic practices

A governing ideal of PD is that end-users of a design should have the right and the authority to influence decisions [55,63]. Influencing decisions requires that designers share their knowledge with the users throughout the design process [50] and acknowledge them as genuine design partners with knowledge equally important to their own [60]. A democratic practice was sought through organising the study in such a way, that the young adults worked closely together with designers when emerging the technology. As part of this innovative partnership, the young adults had the mandate to propose content for the technology, to select the content and to design the content. In some ways the process was in favour of the young adults, and as such non-democratic. One example was that the young adults were always heard before the HCPs, which meant that they directed the process of design. Another example was, that the young adults voted for functionalities in the technology with a stronger voice (1:1,5) than the HCPs. The choice of making the process in favour of the young adults was made to clearly state that they knew best themselves about their problems, needs and preferences for support.

Situation-based actions

A conception of PD is that design actions should be situation based. Rather than understanding the needs and visions for a design through formal abstractions, it should be understood in the context of the environment – or the concrete space [64] - where the design should be used [50]. A PD approach to design, thus, requires the use of field work [55]. Field work was integrated into the research process as participant obsevations [65,66]. Participant observations [65,66] and their application in the study, are described in chapter 5.

Mutual learning

The epistemological stand of PD is that knowledge needed for sustainable design is developed most effectively through active cooperation and collective creativity between end-users of a design and designers [38,52,54]. Users learn from designers about the potentials of the design, and how these may work. Likewise, designers learn from users about the context and objective for design. In this study young adults recently diagnosed with schizophrenia, HCPs and designers collaborated as a team to develop the technology. The arena for their interaction was co-design workshops. Co-design workshops [67] and their application in the study are described in chapter 5.

Tools and techniques

The practice of PD is facilitated trough different tools and techniques to help users create, develop, express and evaluate their ideas and visions without being able to speak the more abstract professional language of designers [50]. Such tools can prompt creativity [68] and enable designers and users to experiment easily with different design ideas in cost-effective ways [69]. As the project leader and PhD student, I facilitated the PD process, and in order to do so, I prepared a toolkit [70–72]. The toolkit was designed with help from a graphic designer and a graphic recorder. Inspiration for the toolkit was found in a research article on motivational aspects of PD in young people [73], and PD literature on telling, making and enactment activities to help those not trained in design to create, develop, express and evaluate their ideas and visions [74–77]. The tools and their uses are shown in **Table 2**. A detailed description of the application of the tools in the study is described in chapter 6.

Table 2. Toolkit to support the practice of PD

Tool	Use of tool
Poster aim	Provide overview of overall workshop aim
Poster agenda	Provide overview of plan and rules for the workshops
Graphic recording [78]	Provide overview by coping information onto large charts that everyone can see
Story board [76]	Template to examine the tacit and invisible aspects of living with schizophrenia and generate ideas
List for thoughts	Template to rank ideas and worries in relation to app use in care
Post-its notes	Provide overview in voting process of app functionalities
Design catalogue	Facilitate discussion about look and feel of app
Mock ups [53]	Template to sketch proposals of what the app will look like
Card sorting [53]	Categorize early signs of illness exacerbation in a category-three
Screen dumps	Facilitate concrete dialogue on app functionalities based on existing mHealth solution
Paper prototypes [75]	Facilitate concrete dialogue based on low fidelity manifestations of ideas and concepts for the app
Word document	Create text and lay-out of content in app

4.3. User-innovation management

The choice of employing a PD approach meant that genuine participation [52] was a matter of constant attention. Therefore, the User Innovation Management (UIM) tool was used to plan the PD process. UIM provides a systematic step-by-step guide to plan participation of users in the design process [79]. UIM is comprised of three themes: 1) cooperation with users, 2) contextual understanding of problem(s), needs and possible futures, and 3) the design of concepts based on users innovations. Each theme is comprised of two UIM steps [79]. The UIM tool made the process of planning transparent and equipped me to have reflexive conversations with my supervisors about approaches to foster participation and all the methodological choices taken in this respect. As an example, the UIM tool initiated dialogue on how to foster participation in the workshops. This dialogue aided the choice of 'recording' the workshop dialogue visually in the moment to compensate impaired memory and attention, which is a common problem in individuals with schizophrenia [80–82]. **Appendix B** shows how the UIM tool was applied in the study to plan user-innovation.

4.4. Facilitation of user-innovation

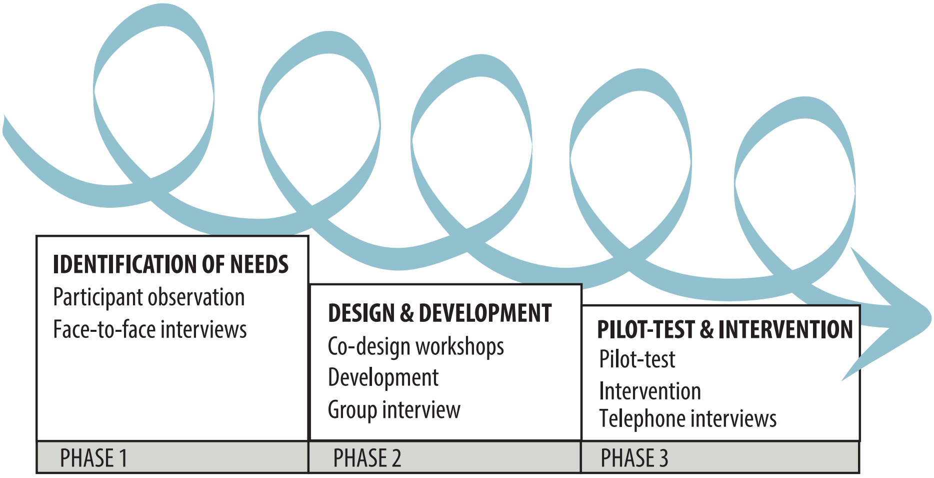
Key to a PD approach is that genuine participation is made possible. As the project manager and PhD student it was my role to make this happen. This required that I practiced a participatory mind-set [77], where I was open and sensitive to the young adult´s perspectives and narratives. While facilitating the workshops I was particularly aware that the literature review but also experiences from previously researching the lives of this study population (master thesis) and my clinical background in young adult schizophrenia care could blindfold me, leading me to believe that I already knew how the technology should be designed to best accommodate the young adult´s needs. I strove to be open and humble by asking for their views, ideas, preferences and experiences and carefully listening to their answers.

4.5. Summary

The research was conducted using a PD approach. The approach was guided by core PD principles, including a toolkit to facilitate user-innovation. User-innovation was planned using the UIM tool, and carried out on the basis of a participatory mind-set.

CHAPTER 5. MATERIAL AND METHODS

In this chapter materials and methods are described for the two objectives. First the setting of the study is defined. Next, methods used to collect data are delineated. Then, a description of the approach used for data analysis and ethical considerations are shared. At the end of the chapter methods and materials are summed up.



5.1. Setting

The setting of the study was OPUS. OPUS is an intensive and evidence based outpatient program, developed specifically for community dwelling young adults aged 18-35 years with a recent diagnosis of schizophrenia [22]. The program is disseminated throughout Denmark, has a duration of two years and provides bio-psycho-social care to prevent illness exacerbation and maintain quality of life, regardless of illness [22].

Participants for the study were recruited from the OPUS program affiliated Aalborg University Hospital – Psychiatry. An exception was one young adult who was diagnosed with schizophrenia before the program was initiated in 2012 (see later). The Aalborg OPUS program covers an area of 7,933 km^2 and offers weekly (home) consultations, medical treatment, group treatment, education in mental illness (psychoeducation) and guidance on healthy lifestyle. Almost all young adults enrolled in the program suffer from severe symptomatology and require close contact with HCPs [83]. Consequently, the caseload is low (1 HCP per 10-12 young adults and their family). When the study was initiated the program was in a start-up phase. In the last phase of the study a total of 98 young adults and four nurses, two psychologists, two occupational therapists, one social worker and one medical doctor were affiliated.

5.2. Materials and methods objective I

The first objective of the study was to identify the needs of support in young adults recently diagnosed with schizophrenia; to design and develop a smartphone technology responsive to their needs; and to test the technology as an intervention in order to evaluate if and how it supports the needs of the young adults in the everyday management of living with the illness.

The objective was explored through a three-phased PD process. Each phase was iterative and moved in a spiral of planning, acting, observing and reflecting. Insights gained in one phase were used to decide how to proceed to the next phase. **Table 3** provides an overview of the PD process, the research questions governing the process, and the data sources.

Table 3. Phases, research questions and data sources

Phases	Research question	Data sources
1: Identification of needs	What are the needs of support in young adults recently diagnosed with schizophrenia and what are their ideas for using the smartphone to accommodate the needs?	Participant observations (45 hours) Face-to-face interviews (n=6)
2: Design and development	What are the specific resources requested to accommodate the needs of support in the everyday management of living with recently diagnosed schizophrenia?	Co-design workshops (n=10)
3: Pilot-test and intervention	How do young adults with recently diagnosed with schizophrenia use and perceive the use of a smartphone app (MindFrame) as a tool to foster power in the everyday management of living with their illness?	Pilot test (6 months) Intervention (12 months) Telephone interviews (n=13)

5.3. Data collection

Participant observations

Participant observations were carried out from October-December 2012. They were conducted to construct an interview guide for subsequent face-to-face interviews and carried out as an inspirational tour [79] to learn about the lives of the young adult´s. As the PhD student and project leader, I conducted the participant observations. I followed the daily work of two nurses and one occupational therapist from OPUS, which included nine home visits and visits to an in-patient clinic for young adults only. A total of 45 hours of participant observations were conducted.

Consent for the participant observations were obtained from the managers in OPUS and the in-patient clinic respectively. The young adults were asked permission to be observed during consultations with their HCP. The HCP handed a description of the overall study to the young adults ahead of the consultations, and when permission had been obtained the observations were conducted. Brief questions were asked during the observations to generate an initial understanding of "care that fits" [23]. As recommended by Spradley, the observations were reported as field notes and documented as objectively as possible [66]. Inspired by Hammersley, field notes were documented with a focus on place, participants, activities and emotions [65].

The participant observations revealed that the young adults strove to be independent and requested OPUS care that enabled them to better self-manage and control the illness on their road towards recovery. Therefore, the interview guide for the face-to-face interviews was constructed around the theoretical concepts of recovery, power, empowerment, care, self-care and self-efficacy. The concepts are defined on page 15.

The guide was thematic [84] and included suggestions for specific questions. It was constructed as sketches of three themes: challenges in everyday living with schizophrenia, 'good care', and the smartphone as a means of support in the management of everyday living. The guide is shown in **Appendix C**.

Face-to-face interviews

Face-to-face interviews were carried out from April-May 2013 to explore the young adult´s support needs and their ideas of using the smartphone to accommodate the needs. Face-to-face interviews were chosen, as they are appropriate to gain rich accounts [85] about an individual´s life-world [84], which was key to set the right direction for the design of the technology.

As the PhD student and project leader, I conducted the interviews. Interviews were carried out with six young adults (2 male, 4 female) from the OPUS program. At inclusion, their mean age was 23,3 years (range 19-27). All had been diagnosed within the past year, received social benefits and lived independently. All owned a mobile phone, which they used on a regular basis.

Two criterions were set for participation. One was a diagnosis of schizophrenia within the past year, as it has been argued that individuals who are not "stuck" with too much experience make excellent innovators [68,86]. The other was willingness to share information and ideas by virtue of knowledge and experience. Criteria for exclusion were inability to speak or understand Danish and unwillingness to provide written consent.

Recruitment was conducted in close collaboration with HCPs from OPUS. The HCPs provided the young adults an information letter explaining the interviews and the study as a whole, and asked them to consider participation. The HCPs asked permission for me to contact them on the phone, to tell them more about the study. All consented to participate, and individual arrangements were made about the date, place and time for the interview.

Based on preference, the interviews were conducted either at the young adult´s homes or at a research facility in Aalborg, Denmark. A Venn diagram [79] was used with the interview to address the young adult´s supportive network. This was in order get an idea of the how the technology should be 'wired' to accommodate their needs of support in a real life setting. The Venn diagram was pilot-tested in the first interview. The pilot-test showed that needs differed significantly on good days and bad days respectively. Consequently, two identical diagrams were used in the following interviews; one to address support on the good days, and one to address support on the bad days. **Appendix D** provides an example of a Venn diagram made by a study participant.

The interviews were semi-structured [87] and conducted using the interview guide constructed on the basis of the participant observations. The guide worked to set direction for the interviews while still pursuing what the participants found interesting within the scope of the research question [88]. To encourage the young adults to speak freely interview questions were open-ended. To secure depth of data, each interview was continued until saturation had been reached [89], therefor the interviews stopped when the narratives became repetitive and no new data was revealed. The interviews lasted between 55 minutes to 1 hour and 18 minutes. They were digitally recorded and transcribed verbatim.

Co-design workshops

Co-design workshops were conducted from May 2013 to February 2014 to explore and develop the specific resources to accommodate the needs of support in the everyday management of living with recently diagnosed schizophrenia. Co-design workshops were chosen as the arena for design of the technology as they can seed positive social connection between participants, immerse participation and foster shared understanding [53,90].

As the PhD student and project leader, I planned, coordinated and facilitated activities and dialogue in the workshops. The young adults who had participated in the interviews were invited to proceed into the workshops as part of a design team. Consequently, the criteria for workshop participation were comparable to those established for the interviews. Three consented to proceed and one was excluded due to pending childbirth. To supplement the group of participants, a young adult with schizophrenia, which was not enrolled in the OPUS program, was recruited. This participant was in recovery and seemed to be a valuable resource to strengthen the group of young adults as she had a longer experience of managing the illness (five years) and a professional background in design. HCPs employed in OPUS and software designers, a graphic designer, a graphic recorder and an IT project leader were part of the design team. They participated until a final concept had been agreed on. No criteria were applied for their participation. The design team and their roles are shown in **Table 4.**

Table 4. The design team and their roles

Participants (n)	**Roles**
Young adults (4)	Generate insights and manifest design ideas
Healthcare providers (7)	Generate insights and manifest design ideas
Software designers (4)	Co-facilitate dialogue and activities and transfer design sketches into app prototype
Graphic designer (1)	Co-facilitate dialogue and activities, logo design and user-interface design
Graphic recorder (1)	Co-facilitate dialogue and activities, visual recording and visual notes
Information technology project leader (1)	Bring together the perspectives of the design team with the IT department and the legal office in regards to rules and regulations on security issues, i.e. data storing and log-in procedures
Team leader = PhD student	Plan, coordinate and facilitate activities and dialogue

The young adults recruited for the co-design workshops were provided an invitation. The invitation was mailed to their home address. The invitation provided the overall aim of the workshops, the timeframe and the setting. Following each workshop they were asked if they wanted to precede to the next workshop, and if they consented, they were provided an invitation on SMS or email depending on preference.

The toolkit (Figure 2) was employed to aid the process of exploring and developing resources to accommodate the young adult´s needs of support in the everyday management of living with schizophrenia. Poster aims, poster agendas and graphic recording was used to create overview in the fuzzy front-end of the design process [75]; storyboard, list for thoughts and card-sorting to generate understandings; screenshots to facilitate concrete dialogue; mock-ups, paper prototypes, and design catalogue to manifest design ideas; post-its notes for voting; and word document to create text and lay-out for app content. **Table 5** provides an overview of the 10 co-design workshop conducted including their focus, participants and tools. Photos of selected tools employed in the workshops are provided in **Appendix E**.

Table 5. Workshop number (no) including their focus, participants and tools employed

No	Workshop focus	Workshop participants (n)	Tools
1	Vision and ideas of using the smartphone for support	Young adults (4) Software designers (2) Graphic recorder (1) Information Technology Project Leader (1) Team leader (1)	Poster aim and poster agenda hanging on wall to provide overview. Storyboard template designed as comic book to describe 'the good day with the amazing app'. Graphic recording of storyboard presentation to discuss and synthesise ideas.
2	Ideas and worries of using the smartphone for support	Healthcare providers (7) Software designers (3) Young adult as graphic recorder (1) Team leader (1)	Poster aim/agenda/synthesised findings (from workshops 1) hanging on wall to provide overview. List for thoughts templates to critically discuss and rank ideas from workshop 1. Graphic recording of presentations.
3	Prioritize ideas, sketch ideas and set out guidelines for look and feel of the app	Young adults (4) Healthcare providers (3) Software designers (2) Graphic designer (1) Graphic recorder (1) Information Technology Project Leader (1) Team leader (1)	Poster aim/agenda hanging on wall to provide overview. Design catalogue with fonts, colours, symbols and signs to facilitate discussions on look and feel. Mock-ups designed a big cartoon smartphone interfaces to sketch envisioned ideas and stimulate discussions. Post-its notes to execute and provide overview in voting process of app functionalities. Different colour notes for HCPs and young adults. Power level 1:1,5 to the young adults. Graphic recording of mock-up presentations.

4	Select parameters and rating scales for assessment feature	Young adults (3) Software designer (1) Team leader (1)	Card sorting to arrange 56 statements of early warning signs [12] in a category three. Screenshots of existing mHealth platform to facilitate dialogue.
5	Sketch web-dashboard visualization feature	Healthcare providers (7) Software designer (1) Team leader (1)	Screenshots of existing mHealth platform to facilitate dialogue. Mock-ups to sketch envisioned ideas and stimulate discussions.
6	Sketch medication overview feature	Young adults (4) Healthcare providers (7) Software designers (1) Team leader (1)	Screenshots of existing platform to facilitate dialogue. Mock-ups to sketch envisioned ideas and stimulate discussions.
7	Sketch action plan feature	Young adults (4) Software designer (1) Team leader (1)	Screenshots of existing platform to facilitate dialogue. Mock-ups to sketch envisioned ideas and stimulate discussions.
8	Elaborate feature	Healthcare provider (1) Team leader (1)	Prototypes to show low fidelity manifestations of ideas and concept for action plan.
9	Develop content	Young adults (2) Team leader (1)	Word-document to create text and lay-out of action plan content.
10	Develop content	Young adults (2) Team leader (1)	Word-document to create text and lay-out of action plan content.

Instead of a hospital setting, an ‘out of hospital setting’ was chosen for the workshops to encourage the young adults to consider themselves as designers rather than patients [91]. Over the course of time, the setting of the workshops changed. The reason for this was that it was easier to plan and execute workshops in the hospital and since the young adults had taken on the role as designers, it was a way to ease my workload. Workshops with young adults only, lasted between 3-7 hours. Workshops with HCPs only, and mixed workshops, lasted between 1 hour and 30 minutes and 3 hours, respectively.

The workshops continued until a technology ready for test had been deveoped. The process of design was driven by a developmental evaluation approach, constantly challenging and testing assumptions, tacit knowledge, and the insights gained in relation to the research question and the overall aim of the study. Such an approach is compatible to the emergent nature of co-design [92]. The tangible 'result' of the workshops was MindFrame. MindFrame consisted of an app for young adults to empower their self-management and a website affiliated with the app to foster collaboration with their HCPs.

MindFrame was developed using an existing technological platform as a framework. The reason for this was, that the early phase of the co-design process showed preferences for resources in MindFrame already developed by Monsenso ApS for the care of individuals with bipolar disorder. The platform seemed a perfect fit, particularly since it had already been technically validated in various clinical evaluation studies and randomized controlled trials (RCTs) [93].

Pilot-test

MindFrame was pilot-tested in OPUS from February to August 2014. The pilot-test was conducted to prepare the intervention, which is a vital part of a PD project [94]. As the PhD student and project leader, I conducted the pilot-test.

An important aspect of preparing the intervention was to take bugs out of the technology; therefore, participants who knew the technology were recruited. The recruitment strategy, thus, was purposive [49]. Two young adults and two HCPs who had participated in the co-design workshops were recruited. The criteria for participation for the young adults and the HCPs, respectively, were willingness to use the app and the affiliated website, and to provide feedback. The secretary from OPUS assigned as technological gatekeeper during the intervention assisted the pilot-test.

As suggested by the literature review, MindFrame was employed as an add-on tool to regular OPUS care. The young adults had free and unlimited access to the resources in the MindFrame app. The app functionalities are shown in **Table 6**. The development of the resources is described in the chapter 6.

Table 6. Resources in the MindFrame app

Resource & aim	**Capabilities of resource**	**Intended use of resource**
Self-assessment to monitor health	Data input to report the mental health state and a note function to explain the assessment scores. Automatic sampling of physical and social activity data through sensors in the phone.	Individual customization of assement list and daily report of health. Data (assessed and sensor) are stored by the smartphone and transmitted automatically to a study server when Internet connectivity is available. At this point data are visible to the HCPs through the affiliated website [96].
Visualization for psycho-education	Data display and sharing to use for education.	Data are shared in the app and on the website. Data is used to explore relations between symptoms, wellness and behaviours. alone or with HCP. The HCP have a tablet with wireless Internet connection and an eternal keyboard to access data on home visits [96].
Early warnings signs to be aware of changes in health	Display of early signs of illness exacerbation and suggestions of how to tackle changes to stay well.	The relapse signature and drill are identified. Customized feedback is provided in order to stay alert of changes [96].
Triggers and alerts to be notified of changes in health	Authomatic data survey to notify signs of illness exacerbation and provision of feedback on actions to take to stay well.	Threshold values are set to survey data e.g. stress level higher than 2 (pretty stressed) in more than two consecutive days. When the threshold values are triggered feedback on actions to take is provided [96].
Action plan on strategies to stay in good health	Display of three levels of relapse prevention strategies; 1) stay well; 2) what can help and; 3) get help.	The actionplan is custimized to fit the individual and used whenever needed [96].
Medication overview to support medication management	Reminders and tracking of medication adherence.	Medication is added to the overview and reminded as part of the self-assessment procedure [96].
Settings to customize resources	Customization of reminders and change of pin-code. Access to user-guide and into film.	Changes made in relation to needs and preferences [96].

During the pilot-test, participants could text, write or phone to report any technological bugs. The claims were forwarded to Monsenso ApS. The process continued until all bugs had been taken out. During the pilot-test the participants were phoned once a fortnight to collect their experiences of using MindFrame. Their feedback was documented as notes.

Intervention

MindFrame was implemented as part of regular OPUS care from January to December 2016. The long intervention period was directed by the pilot-test, showing that one of the young adults had put aside MindFrame in a period of severe symptomatology and resumed it later (see findings section).

As the PhD student and project leader, I was in charge of the intervention, yet, as MindFrame was implemented as part of regular care regime the intervention was handed by the HCPs in OPUS. The criterion for participation in the intervention was enrolment in OPUS, ability to read Danish and willingness to download and use the app. The HCPs in OPUS were in charge of inviting their young adults to use MindFrame. The invitation carefully informed that it was voluntary to use MindFrame, and that it could be used due to needs and preferences. Invitations were provided throughout the intervention period. Thus, the length of the intervention and the time when the intervention was applied in the course of care differed from person to person.

The HCPs in OPUS were responsible for teaching and guiding the young adults in using and customizing the resources in the MindFrame app. Therefore, HCPs received training ahead of the intervention period. The training was conducted with help from Monsenso Aps. The training was group-based and held as a 2-hour hands-on session. The HCPs who were unable to partake in the group training were offered a one-on-one session. After the training session, the HCPs were provided a hard copy of a user guide describing each resource in MindFrame in depth, customization of the app resources, and how to receive first-level support. I was available for questions and supervision throughout the intervention period. Only few inquiries were received. These were documented as notes.

Telephone interviews

Telephone interviews were conducted from January-March 2017 to evaluate use and perceived usefulness of MindFrame as a tool to foster power in the everyday management of living with schizophrenia. As the PhD student and project leader, I conducted the interviews. Initially, the priority was to conduct face-to-face interviews with the young adults who had used MindFrame, but due to time constraints interviews were conducted on the phone. Telephone interviews have shown to be productive in qualitative research [85], yet advantages of face-to-face interviews have been suggested in terms of more precise responses, time to think thoroughly about responses and more self-generating answers [97].

The recruitment strategy was pragmatic and convenient [49]. The only criteron for participation was willingness to share information by virtue of knowledge and experience. The HCPs in OPUS distributed the invitation, and I phoned those consented to be contacted explaining more about the purpose of the evaluation and their right as study participants. Written consent was obtained and agreement of when the interview should be conducted was made on phone, email or SMS based on preference.

Interviews were conducted using an interview guide constructed around the concepts of power and empowerment (see page 15). The guide is shown in **Appendix F**. To encourage the participants to speak freely about their views on how the MindFrame app fostered power in the management of their lives with the illness interview questions were open-ended. However, at the end of the interviews close-ended questions were posed to works around the concept of empowerment and to prompt more direct questions. The interviews lasted between 35-66 minutes. They were digitally recorded using the TapeACall app and relevant parts were transcribed verbatim.

5.4. Materials and methods objective II

The second objective of the study was to investigate whether participatory design thinking and tools could enable young adults diagnosed with schizophrenia to participate and engage in the design of a smartphone technology used to accommodate their needs of support. To this end, I looked at how the workshops (room of design) were constructed and its characteristics. The data sources to explore the objective were as follows:

Workshop invitation (n=1)
Workshop preparation descriptions (n=10)
SMS posted to young adults (n=680)
Emails posted to young adults (n=69)
Workshop notes (n=10)
Written reflection from young adult (n=1)
Group interview (n=1)

5.5. Data collection

Workshop invitation

The young adults received an invitation ahead of the first workshop. The invitation provided information about the aim of the workshop, the time frame (5.5. hours) and the setting (activity centre). The invitation was drawn and requested their specific expertise to design the ‘coolest app’ for early phase schizophrenia care. The invitation was colourful and used appreciative language. **Appendix G** shows the invitation. Subsequent workshop invitations were sent using SMS and emails.

Workshop preparation descriptions

Each workshop was prepared as a script. The script described timeframe, setting, participants, activities, roles, responsibilities and catering.

SMS and emails

SMS and emails were used to invite the young adults to attend the workshops, yet, also to provide reminders of the workshops and to communicate between the workshops. Reminders were provided based on preference. One was not reminded. Another was reminded the day before the workshops using SMS. The two others were reminded the day before the workshop and on the morning of the workshops using SMS.

Workshop notes

During the workshops, notes were taken. In particular, they regarded the use of the tools in the toolkit. Hence, the notes focused mainly on methodology.

Written reflection from a young adult

Originally it was thought that the young adults should reflect on their participation in the co-design process, at the end of each workshop but they did not have the surplus energy to do it, and requested to do it at home. They were emailed seven questions regarding their role, the setting, the user-activities, their learning´s and their ideas for making the workshops better. Only one reflection was handed in, and it was decided with the young adults to do a group-interview instead.

Group interview

The group-interview was carried out following workshop 6. This was in December 2013. A group interview is appropriate when exploring people´s experiences and understandings of phenomena. The benefit of a group interview is that it can mobilize association, thereby taking advantage of the group dynamics when exploring experiences and understandings [49].

The recruitment strategy was purposive and pragmatic [49]. The only criterion for participation was attendance in the workshops and willingness to share information by virtue of knowledge and experience. Since all had consented to participate, the invitation was delivered on email and SMS.

The group interview was conducted using the same questions as in the reflection sheet. The setting of the group interview was a conference room in the OPUS clinic, which was well known to the participants. To facilitate a relaxed atmosphere, drinks and candy were provided. The interview lasted an hour, was tape-recorded and transcribed verbatim.

5.6. Data analysis

As the PhD student and project leader, I analysed and interpreted data. The first analysis was made with help from one of the supervisors. The remaining was made unassisted. The last author of each article assisted with the interpretation of data.

In Gadamer´s understanding, interpretation is not a stepwise approach. Consequently, he does not provide a method for analysing data, i.e. interview transcripts, words on tapes, observations and notes [48]. Nevertheless, he states that a systematic approach is needed in order to research understanding [47]. To provide structure in the process of analysis, inspiration was found in four guiding tasks proposed by Fleming et al. [48]. The tasks, which are derived from Gadamer's work, are grounded in the hermeneutical circle. They regard; finding fundamental meaning of the text as a whole; exploring parts for meaning; comparing the meaning of the whole with the parts; and identify passages representative of the interpreted meaning.

Process of analysis

Guided by hermeneutical thinking, the analysis begun with reading through interview scripts and listening to tapes multiple times to obtain a fundamental meaning of the text as a whole. Then the fundamental meaning was split into smaller parts, which were explored by reading or listing them into smaller sections, and individual sentences. To obtain meaning from the section and sentences, they were deconstructed through interpretation, and the interpretation was constantly compared and contrasted to the meaning of the whole.

It is argued that understanding remains transient, this means that the researcher can continue indefinitely in moving between parts and the whole [48]. The hermeneutical process continued until an inner unity of text, that was free of logical contradictions, had been reached. At this point, categories of synthesised meaning were constructed. As a final task, passages of text representative of the interpreted meaning were identified. This is important to establish trustworthiness of the research process and truthfulness of the analysis [48]. The passages are presented as quotes in paper I-III.

5.7. Ethical considerations

The local ethics committee reviewed the study. In accordance with Danish law, a formal ethics approval of the study was not required. Authorization by the Danish Data Protection Agency (Datatilsynet) was obtained (2008-58-0028).

Recruitment of young adult participants for phase 1 and 3 was conducted by HCPs in the OPUS clinic, who were known to the participants. Participants were provided written and oral information about the overall study and the specific part for them to participate in. They were given time to think about participation before they gave there written consent. When written consent had been obtained, I contacted the participants either by phone or SMS to tell more and to make further arrangements. In line with good ethical practice in qualitative research with vulnerable populations, consent for participation in the workshops was confirmed orally prior to each workshop [98].

The study was consistent with the Declaration of Helsinki [99], meaning that the participants were carefully explained: 1) that participation in the study was voluntarily, 2) that withdrawal from the study was possible at any given time and, 3) that withdrawal would not impact the future course of care in the OPUS program. The participants were assured anonymity and confidentiality when presenting findings, though accepting the possibility that their HCPs in OPUS would be able to recognize them.

5.8. Summary

Objective I was explored through a three-phased PD process. Each phase in the process was iterative and moved in a spiral of planning, acting, observing and reflecting. Insights gained in one phase were actively used to decide how to proceed to the next phase. Data were collected by means of participant observation, interviews, co-design workshops, pilot-test and intervention. Objective II was explored on the basis of data generated in phase 2. The approach to data analysis was hermeneutic and grounded in the hermeneutical circle. The study was consistent with the Declaration of Helsinki.

CHAPTER 6. FINDINGS

In this chapter the findings of the study are summarized on the basis of paper I and II and III, including additional non-published findings. First, the findings related to objective I are summarized. Then, the findings related to objective II are summarized.

6.1. Objective I

To identify the needs of support in young adults recently diagnosed with schizophrenia; to design and develop a smartphone technology responsive to their needs; and to test the technology as an intervention in order to evaluate if and how it supports the needs of the young adults in the everyday management of living with the illness.

6.1.1. Needs of support and ideas for accomodating the needs

Low levels of knowledge and high levels of uncertainties were a shared matter among the participants, bringing about a vast need of support in order for them to gain power over their new life-situation. Ideas for using the smartphone to foster power were; in-situ guidance; recovery tracking; notification of illness exacerbation; wired list of medications; on-demand information; and online lifeline [100]. The ideas are briefly summarized in the following section. A full description is available in paper I.

Six ways to foster power

In-situ guidance

The participants emphasised how they sometimes felt powerless and helpless in managing the illness and their new and changed life-situation. All had received (psycho) education to better understand and cope with the illness as part of their course, either alone or in groups. They stressed that education was truly important to become in charge of the illness rather than a victim of it, yet they emphasized how they often felt incapable of translating the knowledge obtained in the 'classroom' into action. They indicated the need to have easy access to a resource that could guide them 'in-situ' to self-manage the illness appropriately and proactively. This, they stressed, was particularly important since the OPUS program was restricted to two years, putting a pressure on them to learn what to do and how to act unassisted by help, in the long run [100].

Recovery tracking

The participants stressed how cognitive impairments were a central feature of the illness, and how severe impairment of memory and attention made it hard to recall their own progress. Since experiences were no longer stored in the memory, often the good days faded or disappeared. This greatly impacted the hope of recovery, as it became difficult to believe that things eventually would change for the better. Several of the young adults explained how their HCPs had encouraged them to monitor their health to keep track of the their own progress in order to easier call to mind the good days, and one participant proposed that tracking of the recovery process could help to recall and tell apart the good and the bad days, respectively. This, he believed, could keep up the hope of recovery [100].

Notification of illness exacerbation

The participants described how fear of illness exacerbations was a matter of persistent concern. They stressed how it was hard to find out which information from the senses they should pay attention to, which left them watchful 24/7 – worried and controlled by the illness, rather than certain and in control of it. They requested a kind of warning that would tell them when to be alert. This, they emphasised, could promote a sense of confidence and control in their life with the illness, but also help to take time off from the illness, and to focus on being young rather than being ill [100].

Wired list of medications

The participants stressed how the severe impairment of memory and attention not only impacted their hope of recovery, but also their ability to keep track of their medications. They requested to have a list at hand that could empower them to control and remember past and present types and doses of psychotropic drugs, particularly in stressful situations [100].

On-demand information

The participants described a widespread need for timely information, paticularly in the time following the diagnosis when the level of knowledge was low and the level of uncertainties high. They explained how they had turned to websites to look for information. This included information on the nature of schizophrenia, treatment options, recovery rates and psychotropic drugs. In addition, it included information on tips and tools to fight and manage the illness and the new life situation independently. Yet, they found the information hard to comprehend, and they requested easily comprehendible on-demand information to keep a sense of perspective in the process of preparing for the time to come [100].

Online lifeline

The participants described how their phone served as an online lifeline to the HCPs, making help and guidance feel within reach, even out of business hours. Getting things off their chest by writing them, and knowing that the HCPs would reach out with qualified help and support, empowered them to better manage late and difficult hours independently [100].

Summing up, the findings demonstrate that young adults with a recent diagnosis of schizophrenia require comprehensive support to become empowered to confidently manage their new and changed life situation. The smartphone holds this potential by offering flexible collaboration and timely access to self-management resources.

6.1.2. Smartphone technology resources to accomodate the needs of support

The smartphone technology (MindFrame) was designed with the design team to encourage self-management and collaboration by means of health monitoring, customized psychoeducation, awareness and notifications on changes in health, strategies to stay in good health and medication management support.

As earlier evidenced (table 6) a key aspect of MindFrame was health monitoring. The intention of health monitoring was that self-assessment scores should be used to track recovery, to notify changes in health, to support medication management and to educate the individual on how to manage everyday living with the illness. Therefore, parameters to stay on track with the illness were identified. Card sorting revealed five mandatory parameters and 11 optional parameters of relevance to monitor.

The mandatory parameters regarded state of the day, level of activity, quality of sleep, medicine consumption and stress level. The optional parameters regarded alcohol consumption, hallucinations, hashish, isolation, exercise, hygiene, paranoia, self-harm, self-medicating, sensitivity and use of drugs. In order for MindFrame to be relevant to personal problems, the young adults stressed how they wanted to assess parameters that were only relevant to them. Therefore a template for self-designed parameters was made available in the app. As an example, one wanted to track how many loafs of bread she had in her kitchen, as she knew that bread baking was one of her early signs of illness exacerbation. Another wanted to track the number of cigarettes smoked on a daily basis to try to keep smoking at a minimum.

Assessment scales were defined for each of the predefined parameters and a selection of scales were developed to choose from for the self-defined parameters. The young adults felt it was too hard to rate themselves on a 7 or 10 point Lickert scale. Consequently, a scale ranging from minus 3 to plus 3 was developed. On this scale, point 0 worked as a personal baseline. The plus and the minus score indicated whether the parameter was either above or below average. The web-display of the self-assessment scores was designed with the HCPs. The Monsenso platform displayed data for four days, yet illness exacerbations in schizophrenia often develop over longer periods of time than in bipolar disorder (the illness to which Monsenso was originally developed). Therefore, the HCPs requested for data to be displayed for two weeks, which was the same time span visualised in the app. This, they felt, was needed to spot changes and to react proactively, in order to support the young adults to stay on track.

Another key aspect of MindFrame was easy access to self-efficacy strategies to stay in good health. Therefore, a customizable action plan regarding effective problem solving and prevention of illness exacerbations was developed. Screen dumps of the action plan resources in Monsenso made clear, that it was primarily designed to be reactive (what to do when the illness had exacerbated) rather than proactive (how to stay well). The young adults requested a staged action plan for prevention of psychotic relapse that first and foremost focused on staying well. The mock-up action plan was designed as a reversed traffic light with three stages of support; 1) stay well (green); 2) what can help (yellow); and 3) get help (red). Two of the young adults developed content for the plan. To this end, a HCP from OPUS provided feedback, and contributed ideas based on the stress-vulnerability model [101]. The model, which forms the basis of knowledge and skills education in the OPUS program, proposes that relapses can be prevented by lowering the biological vulnerability and by adapting coping skills and getting social support to reduce stress [102].

At the end of the design of MindFrame, the logo for the app had to be developed. The young adults were specific that the logo should "be all but hospital blue". They associated the colour of blue with illness and dependency and wanted the logo to be bright orange, that to them, reflected hope and recovery. Orange, however, was the colour of the special sector in the municipality of the region, thus, not an eligible colour in the hospital setting. Therefore, the logo ended up being blue with orange letters.

A question discussed early in the design process was, whether a peer-to-peer resource should be integrated into MindFrame. The young adults strongly emphasised the value of emotional and informational support from likeminded people, and came up with the idea of an "inspirational bank" where individuals enrolled in the OPUS program could talk to each other, chat, pose questions and share tips and tools, articles, pictures, drawings and personal stories of recovery. They proposed to design the resources somewhat like the Danish website DepNet, which is a virtual meeting point for people suffering from depression [103]. A peer-to-peer resource was sketched and discussed. Conversations revealed concerns among the young adults and the HCPs that too many individuals enrolled in OPUS would not have the surplus energy to contribute actively on the website. This, they feared, would make the website un-inspirational, but also make it hard to remain anonymous. Consequently, the idea was rejected and not implemented.

A simplistic visual illustration of the MindFrame system is provided in **Figure 2**. MindFrame screenshots are provided in **Appendix H**.

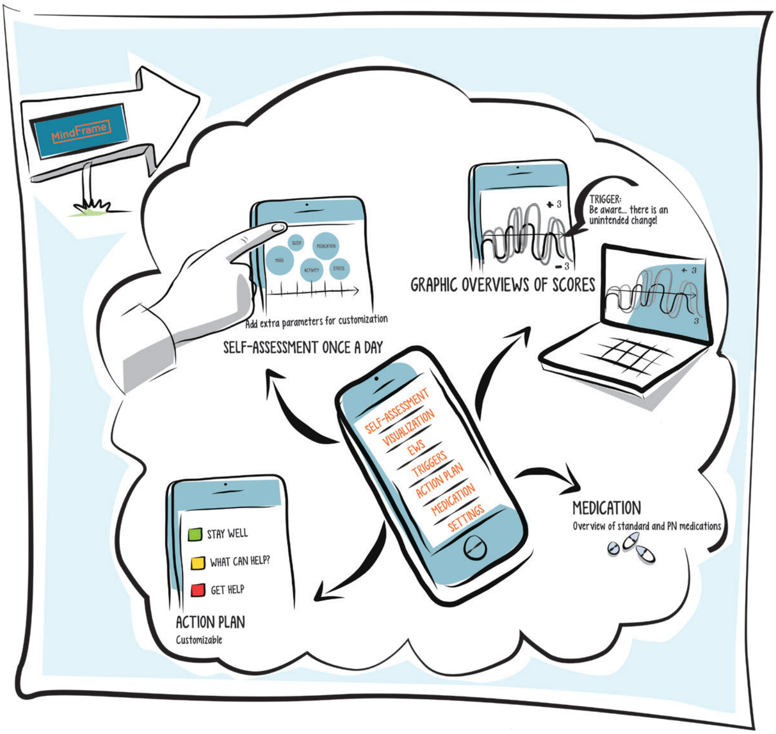


Figure 2. Visual illustration of the MindFrame system

6.1.3. Pilot-test of the smartphone technology

The pilot-test conducted to prepare the intervention showed that MindFrame was easy and intuitive to use. There were no problems using the app, accessing the website affiliated the app, logging in or registering users. Analysis of feedback notes revealed three main learning’s that was taken into account in the intervention. The learning’s regarded adoption of the new working routine, length of the intervention and instability of app functionalities. The learning’s are described below.

Adoption of the new working routine

The adoption of MindFrame intervened with the existing care routine. The HCPs had to log into the website on a daily basis to closely monitor the young adult´s health. Yet, they did not do this. When asked, they owed this to forgetfulness. When the self-assessment scores were not regularly checked it posed a potential risk that the HCPs would miss when a mental health state was worsening. One of the young adults told of how she had stopped making self-assessments in a “bad period” and expected that not providing data was a way of indirectly telling the HCP that she was not well, and needed help. The HCP however did not reach out to help, leaving her with a feeling of being powerless and alone. To safeguard the ethics of MindFrame use, the HCPs decided to apply a working routine for the following intervention where self-assesments should be assessed every morning when preparing the days work. The HCPs and the young adults decided that mutual expectations of using MindFrame in the course of care should be carefully negotiated between the patient and the HCPs, and eventually documented in the patient’s health chart to make sure that all knew their role and responsibilities. The learning was integrated into the MindFrame user-guides developed for the intervention.

Length of the intervention

Engagement with the MindFrame app fluctuated over time. One of the young adults told how she had put aside the app for a period of time and resumed its’ use later. This learning influenced the decision to have a long intervention period, in order to obtain a realistic picture of its use and usefulness in real life setting.

Instability of app functionalities

When MindFrame was piloted an update of the steering system to control the app was executed by Android. The system update made the app unstable. Simply, some of the functionalities did not work properly. It did not make sense to use a version of MindFrame in the intervention that did not work properly, which led to the decision to redevelop the app. The app was redeveloped to run on both the Android and the iOS platforms. Even though this delayed the intervention, it seemed the only right thing to do, as the region hosting the intervention had a ’bring your own device strategy’ and approximately half of the individuals in OPUS were iPhone users. A redeveloped version of MindFrame was released in November 2015. Basically it was equal to the first version. The functionalities were the same, yet the look and feel had been improved. I conducted user tests in close collaboration with the software designer from Monsenso to take bugs out of the system. The process continued until late December 2015.

6.1.4. Use and perceived use of the smartphone technology

Use of MindFrame

A total of 98 individuals with a recent diagnosis of schizophrenia were eligible to use MindFrame, 27 used it. One individuals was excluded from using it as a result of not being able to speak Danish, and 50 refused to use it. In 20 cases, individuals were not invited by their HCPs to use MindFrame. When asked why, the HCPs owed the decision for exclusions to concerns that these individuals were too ill to use and engage with the app. Out of the 27 individuals who used the app, 13 participated in the evaluation. Nine were females and four were males. Their mean age was 24,8 years [96].

The participants in the evaluation described MindFrame as easy and intuitive to use. The period of MindFrame use differed among the participants in accordance with their needs and preferences. Some (n=5) terminated use within 1 month, others (n=4) terminated use within 2-3 months, yet others (n=4) used the app for 6-12 months and terminated their use when the intervention period stopped. Reasons given for self-initiated termination of MindFrame included boredom, lack of motivation and energy, fatigue, and problems quantifying their mental health [96].

Perceived usefulness of MindFrame

From the analysis of the interviews, two main and very different themes were generated about the usefulness and impact of MindFrame. When MindFrame was used with HCPs consistently for more than a month, it could provide the participants with the power to keep up their medication, to keep a step ahead of their illness, and to get appropriate help based on their needs. This empowered them to stay on top of the illness, thus in control of it. Yet, MindFrame could also fuel the fear of restraint and illness exacerbation, thereby disempowering some from feeling certain and secure. This was observed when MindFrame was applied early in the course of care when the participants barely knew their HCP [96]. The findings are briefly summarized in the following section. An extended version of the findings is available in paper II.

Power to keep up medication

The participants who received medication for their illness emphasised MindFrame as a means to keep up their medication, so to stay well. Power was gained from using the self-assessment procedure passively as a reminder to take medication. In addition, it was gained from making use of self-assessment scores to guide the choice of adhering to the medication regime in order to stay in good health [96].

Power to keep a step ahead of the illness

The participants stressed how they feared illness exacerbation and needed to react in a timely matter in order for the illness to stay within their control and emphasised how MindFrame provided them with the power to keep a step ahead of the illness, by making them aware of when to act and how. They explained how power was gained when self-assessments had been conducted for more than a month and in particular when self-assessment was used with triggers and a customized action plan [96].

Power to get appropriate help based on needs

Shared for the participants were cognitive difficulties caused by the illness, making it difficult to recall their mental health over time. Yet, the participants emphasized how MindFrame had empowered their memory to keep better track of their mental state and progress. This enabled them to share it with their HCP, which empowered them to get appropriate help based on their needs. In order for MindFrame to foster fast and timely help, self-assessments should be conducted continuously for more than a month and actively discussed with the HCP. To this end, the participants stressed how they wanted their HCPs to make more use of their scores [96].

Increase of fears and worries of restraint

For some participants, MindFrame increased fears and worries, which disempowered them from feeling confident and safe. This was observed in three participants who had recently been diagnosed and barely knew their HCP. These participants were concerned that monitoring and data sharing could be used by the HCP as surveillance and feared how this could lead to restraint in their bad periods. Yet, the fear of surveillance faded with use of MindFrame in all but one of the participants. This participant embellished his data for the better, in order to stay in control [96].

Increase of uncertainties about the mental health state

The participants highly valued being a step ahead of the illness. Two participants stressed that notifications had given attention to signs of change in their mental health state. On the one side this was comforting as it aided timely actions to prevent exacerbation. On the other hand it was sometimes stressful as it left them wondering if their condition were worsening. The participants emphasised that their uncertainty often disappeared when notifications were shared and discussed with their HCPs [96].

6.2. Objective II

To investigate whether participatory design thinking and tools can enable young adults diagnosed with schizophrenia to participate and engage in the design of a smartphone technology to accommodate their needs of support.

6.2.1. Participatory design to foster participation and engagement

Analysis of the data sources generated in the design process showed that PD aided the construction of a fruitful environment – a room for design – that enabled the young adults to participate and engage in the design of the technology. As such, PD was a powerful practice, which made the young adults strong collaborators. Engagement was related to, 1) a pre-narrative about a community of practice (COP); 2) the room for design as a COP and; 3) the COP as a practice of special qualities [83].The findings are briefly summarized in the following section. An extended version of the findings is available in paper III.

A pre-narrative about a community of practice

The participants experienced the essential elements of a COP (community, domain and practice) ahead of the design process. The experience of a COP arose from a pre-narrative (invitation) expressing a chance to contribute as part of a community of young adults, to a domain of technology development, through a collaborative practice where they were emphasised as knowledge resources and partners of need to develop the best possible solution of a smartphone technology [83].

The room for design as a community of practice

The room for design materialized as a COP, where the participants experienced a sense of domain, community and practice, respectively. The sense of domain came from the developmental work, which the participants greatly appreciated. They described how the domain gave them a shared responsibility to make decisions, but also to innovate and emerge something tangible, which helped to discover and realize own capabilities, competencies and skills. The sense of community came from collaboration. The participants described a strong affinity to the community, which came from being together, doing things together, but also from being acknowledged as a knowledgeable and 'normal' person. The affinity was owed to the composition of the community with likeminded people, which made it one of understanding, acceptance and inclusiveness. The sense of practice came from the physical workshop setting, which the participants perceived to be a healthy and illness-free environment [83].

The community of practice as a practice of special qualities

The room for design was structured with four qualities: transparency, flexibility, security and informality. Transparency was related to predictability. Predictability was provided through communication of the aim, content and timeframe of workshops prior to and on the day of the workshops. Flexibility was related to the freedom to leave workshops if needed, hence the law of the two feet. Security was related to customization of support to engage in the user-activities. For one participant this included gluing away the suns in the storyboard, as she never "got up with the sun and in bed with the sun." For another participant this included writing on the storyboard, as he was dyslexic. For yet another participant this included presenting the storyboard, encouraging her to speak up. Informality was related to the environment of the workshops. Informality grew out of an unpretentious physical environment but also from a liberating tone that was supportive to 'daring' [83].

6.3. Summary

In sum, the study:

- Identified a need for increased capacity and confidence among the young adults to gain power over their new life situation.

- Designed MindFrame to empower self-management of the new life situation by means of health monitoring; customized psychoeducation; awareness and notifications on changes in the health; strategies to stay in good health; and medication management support.

- Identified that the HCPs were reluctant about MindFrame use. In the pilot-test they forgot to review the young adult´s self-assessment scores and in the intervention they opted out 20% (20/97) of the eligible users to decide for themselves whether or not to use MindFrame.

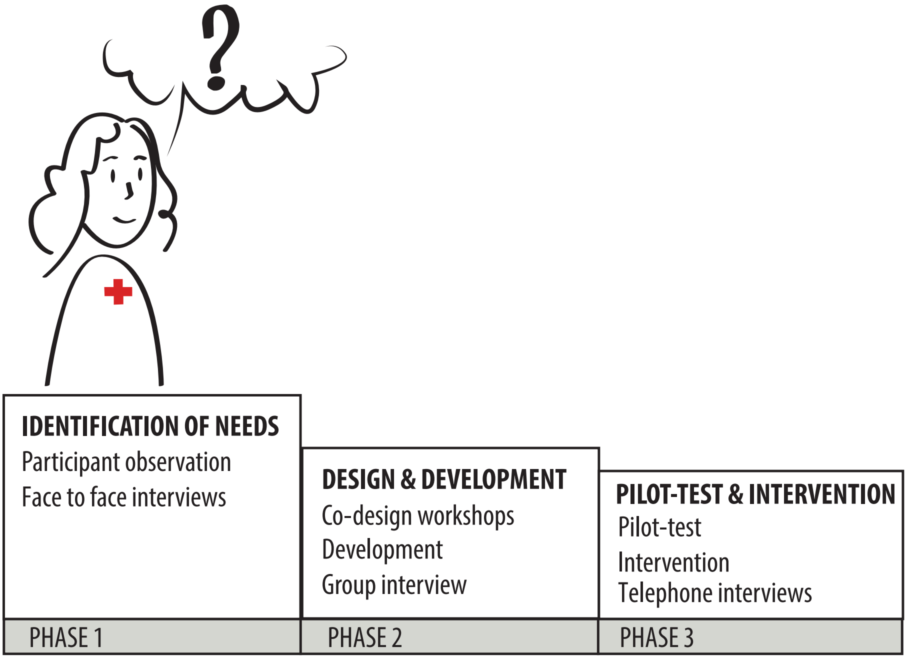
- Identified that the young adults were also reluctant about MindFrame use. Only approximately 35% (27/77) of those invited to use MindFrame chose to use it and 38% (5/13) of the users who participated in the evaluation interviews terminated use within one month due to e.g. boredom and fatigue.

- Identified that the young adults who used MindFrame with their HCPs and consistently for more than a month were empowered to keep up their medication, to keep a step ahead of their illness, and to get appropriate help based on their needs. Yet, MindFrame could also fuel the fear of restraint and illness exacerbation, thereby disempowering some from feeling certain and secure.

- Identified that PD thinking and tools aided the construction of an engaging room that enabled the young adults to become strong collaborators in the design of MindFrame. The room had the characteristics of a COP and the special qualities of transparency, flexibility, security and informality. The COP was not only efficient to emerge MindFrame, it was also efficient to aid the young adults to discover and realize their own capabilities, competences and skills. In that sense it worked as an engine for learning and the construction of an identity as somebody of worth and value.

CHAPTER 7. DISCUSSION

In this chapter a discussion is provided. First, the principal findings are discussed with reference to the aim of the study and previously conducted research. Next, the research approach is discussed. Then, the reliability, validity, transferability and generalizability of the findings are discussed to establish the quality of the study.



7.1. Discussion of findings

Need of power

The young adults requested mHealth resources to increase capacity (knowledge and skills) and confidence (self-efficacy) in everyday management, hence patient empowerment resources [4,5,104,105]. The request correlates previous research. As an example, Schlosser found that individuals with recent onset schizophrenia requested a mobile app intervention to help them obtain more control of their future [106]. The same request was documented by Granja et al. Based on 221 studies on implemented mHealth tools, they established that individuals with schizophrenia valued interventions that targeted patient empowerment and self-management the most [107].

The request for digital empowerment highlights that individuals with schizophrenia want to be active partners in the management of their own health and are eager to develop their self-efficacy to succeed in doing so. This shows that young adults are no different from other diagnostic groups of individuals with long term conditions, who also want ownership of their self-management [105,108] and want to find their own way of living with their conditions [109].

Empowering aspects of MindFrame use

Resources in MindFrame were useful to foster power in the everyday management of living with schizophrenia, given it was used continuously for over a month and with the HCPs. Yet, not all used MindFrame continuously and with the HCPs. Findings revealed that five out of 13 participants in the evaluation terminated MindFrame use within the first month, showing that the personal value of the technology was not always considered strong enough to foster use [96]. This shows, that co-design of an app with the intended user group does not necessarily encourage or motivate adoption, as suggested in the literature [106, 112–115]. The study clearly shows, that in the case of young adults recently diagnosed with schizophrenia more than co-design is needed to adopt an assistive technology into everyday management of living with the illness. Adoption seems to be highly dependent on external motivation, considering the several reasons provided for self-initiated termination (e.g. lack of motivation and energy, boredom and fatigue), which are closely related to the nature of schizophrenia [81]. Yet, also considering earlier research showing, that individuals of younger age (18-29 years) had fewer days of on-demand use of an app to facilitate symptom management, mood regulation, medicine adherence social functioning and improved sleep than older participants (30-45 years and 46-60 years) with schizophrenia spectrum disorder [145].

Offhand, the HCPs seem to be key players in fostering use, yet, as evidenced in both the pilot-test and the intervention, the HCPs had a hard time adopting MindFrame into their working routine. Similar adoption problems were noted by Španiel et al., in a study using an information technology aided program of relapse prevention in schizophrenia [116], and by Veerbeck et al., in a study using a web-based system for routine outcome monitoring in adults 65+ years with mental health problems [117]. It has been argued that successful implementation of smartphone apps into the care regime for young adult with schizophrenia highly rely on provider uptake [118]. This is strongly supported by this study, highlighting the need for further research to address the adoption issues.

Disempowering aspects of MindFrame use

The study identified two disempowering aspects of MindFrame use. The first aspect was that health monitoring could fuel the fear of restraint thereby disempowering the sense of certainty and security. This was observed in three participants when the technology was applied early in the course of care, when they barely knew their HCPs [96]. In all but one of the participants, the fear faded when they familiarized with the technology and the HCP, indicating that certainty may develop with use over time [119].

Interestingly, one participant embellished his data out of fear of restraint. Simply, he was worried that reporting his true state of mind would authorize the HCPs to admit him to hospital against his will [96]. This aspect of use shows, how an object for monitoring, despite caring intentions, may influence some into guarding themselves. This suggests that mobile monitoring may be restricted in young adult with severe paranoia. Not as a result of inability to navigate a technology, as suggested in previous research [120], but because of positive symptomatology. Ben-Zeev et al., tested a multimodal data collection system to aid in continuous remote monitoring and identification of subjective and objective indicators of psychotic relapse [144, 31] and found that approximately 20% (4/20) felt that sensing made them upset [33]. This underlines that mobile monitoring may disempower certainty and security, even when monitoring is done automatically. This highlights that even though individuals with psychosis are amenable for using a variety of technologies, when symptomatic [121], use should be carefully considered and continuously evaluated to make sure that monitoring is not adding negatively to the management of the new life situation.

The second aspect was that notifications incoherent with the participant´s perception of their mental health could increase uncertainties, thereby disempowering them from feeling self-confident and on track with the illness. This was observed in two participants, who dealt with doubt and hesitation on a daily basis. In these cases, false-negative notifications made them ruminate about possible deterioration and uncertain of whether they could rely on their own sense of health [96]. This observation is in line with findings from the field of chronic obstructive pulmonary disease care, showing how both false-negative and false-positive notifications may lead to emotional responses of disturbance [122]. As evidenced in the previous section worries related to health monitoring appear rather common in individuals with schizophrenia [33]. This highlights the paramount importance of HCPs continually gauging threshold values with the user, in order for the technology to become a powerful tool in their care. Ben-Zeev et al., [123] stress that evidence-based mHealth apps will be downloaded directly onto the smartphone in the future and used by individuals with little or no contact to mental health care facilities. This study suggests that in the case of young adults recently diagnosed with schizophrenia, this may leave some worried and uncertain [96]. This underlines the paramount importance of the active role of the HCPs for smartphone-based care to become a safe and ethical practice.

Power of smartphone-based care
With knowledge from phase 1, 2 and 3, it may be argued that smartphone-based care is viable, but also powerful to support young adults recently diagnosed with schizophrenia in the everyday management of living with the illness. Of note for the future of smartphone-based young adults schizophrenia care is, that successful implementation and long-term adoption requires integration into clinical care settings so that it is relevant and personalized to each individual and their treatment plan [15]. This requires that HCPs start to use person reported data consistently as the basis for the partnership with the individual, but also as a learning tool with colleagues.

An important aspect to pay attention to in the future of smartphone-based young adult schizophrenia care is, that person-centred empowerment and self-management efforts may lead to over-involvement in own care [4] thereby leaving the individual with too big a responsibility for their own health. Thus, putting ‘health care´ [26] or prevention [124] into the pocket of young adults with a recent diagnosis of schizophrenia may be a burden, rather than helpful, if not used at the right time and as part of a close and collaborative partnership with the HCP.

Participatory design beyond engagement
PD thinking and tools aided the construction of a fruitful room for the design of MindFrame [83]. The findings established that the room for design was one of linger; a safe space that did not activate the ‘law of the two feet’, but grounded the two feet, so to say. The lingering effect of the room is interesting, particularly due to the fact that prolonged engagement in the mental health clinic is hard to establish in young adults diagnosed with schizophrenia [20]. The Norwegian Nurse Philosopher, Kari Martinsen, talks about spaces and architecture as preservers of human dignity [125]. This study suggests that the room that arose from collaboratively developing the technology fostered and preserved the feeling of human worth, which made the room one of value, thus one to invest time and energy in. Yet, the room also aided the participants to discover and realize their own capabilities, competencies and skills [83]. As such, it assisted the development of a healing environment [126] that offered an empowering and alternative frame for understanding one’s self. In that sense, the room supported the participants to rebuild and redefine a positive sense of identity [9,126] and to grow beyond the illness [127]. This suggests that PD tools and techniques are valuable not only in designing mental health care, but also in supporting personal recovery: the process of rebuilding a meaningful life in the context of living with mental illness [128]. This supports the notion that participation in the design of a technology may be even more powerful than using it. This highlights the relevance of looking further into potential of PD methodology to establish rooms that can act as learning environments. This could provide ideas for new and innovative ways to work with patient empowerment and facilitation of the journey towards recovery.

7.2. Discussion of research approach

The research was conducted using a PD approach. One, however, may ask, whether the research was ‘truly participatory´ in a PD sense. This will be discussed by turning to the level of participation in the different phases of the study. In phase 1, the young adults engaged as study objects and respondents. Participation was indirect and sought in order to better understand their needs and preferences as a basis for the design of the technology. In phase 2, the young adults engaged as partners in the design of the technology. Participation was direct and sought in order to arrive at a solution accommodating their specific needs and preferences for support. In phase 3, the young adults engaged as respondents. Participation was indirect and sought to understand its potential from the viewpoints of those using it as part of their daily lives. Thus, participation in the research process was both indirect and direct. From the viewpoint of Spinuzzi [7] it may be argued that the study was truly participatory, as ALL activities in the PD process served to develop the technology. The same may be argued if 'genuine participation' is evaluated on the basis of the standards set by The Danish Knowledge Centre for User Involvement in Health Care (ViBIS). They stress that in order for a study to position itself as participatory, the knowledge obtained from an involvement process should be used in practice and ultimately evaluated [129]. This study did both. The MindFrame technology was built around knowledge from young adults with schizophrenia, used as part of their care, and evaluated to render the potentials visible.

Participatory design as an approach to empower voice

The PD process revealed that on a continuum of engagement [130], or a ladder of participation, [131] the young adults were willing and able to participate as collaborative partners in the development of MindFrame. Yet, the findings showed, that in order to become active partners, tools from the toolbox had to be adapted to the individual. The need for individual adjustment of the toolbox clearly shows that the power of voice does not necessarily come from just applying PD tools and techniques in a design process. Rather, it comes from adapting the tools in a way that enables participants to fully participate, which has also been stressed by Kanstrup and Bertelsen [79]. This underlines that the power of voice is related to in-the-moment facilitation, as situations have to be interpreted and acted upon as they arise. This requires the user innovation manager to watch, listen, learn and improvise whenever needed, but also to be self-critical and self-aware in order to develop an informal environment where the participants are willing to use their voice.

Participatory design as an approach to share power

In the design, development, and evaluation of MindFrame, the young adults were provided authority to create choice; to select among them (decide); to concretize the choices (so to make) and; to evaluate the decisions and the final design [60,132]. Yet, two obstacles of power sharing were identified.

One obstacle became clear when the app logo was designed. As evidenced in the methods section, the young adults were explicit in stating that they wanted the app logo to be orange, that to them reflected hope and recovery. Orange, however, was not an eligible colour due to rules and regulations in the region. As such, the power of choice was restricted by local policies, not the designers. The experience was a reminder that participation can easily fall short of its promise to provide a direct and 'more-than-tokenistic' say in design [133] when a solution space does not align with organizational policies and regulations. The young adults felt it was worth the effort to 'fight the battle' and a letter was written to the top management department in the region sharing the problem. In the name of democracy the region somewhat bend the 'colour policy', and the app logo ended up being blue with orange letters. This was a perceived 'victory' by the young adults and the restriction in power ended being an empowering resource, by fighting the battle together. Presumably, this 'struggle' has been productive to the engagement in the design process outlined earlier in this chapter.

Another obstacle became clear in the evaluation of the final design, where HCPs had to invite the young adults enrolled in the OPUS program to use MindFrame as part of their care. In 20 cases an invitation to participate was not provided. As such, a rather large proportion of the eligible participants were never given the authority to decide for themselves whether or not they wanted to use and evaluate the technology. This shows that power challenges are not only related to the application of specific methods in a PD study, but also, to the design of a study. Likely, another recruitment procedure could have reduced this obstacle.

The role of the researcher in the participatory design process

MindFrame was developed through an iterative and collaborative design process where assumptions, tacit knowledge, and the insights gained, were constantly challenged and tested. The iterative nature of PD is very much in line with the hermeneutic standpoint, in that the technology emerged in a dialectic process of moving between parts (individual perspectives) and the whole (co-created knowledge). As the PhD student and project leader, I formed part of the interpretative process, which raises the question whether MindFrame was simply a reproduction of my own pre-judices. One might never be able to fully disprove this; yet, I will argue that the technology occurred through mutual interaction and was a solution based on merged ideas. Throughout the design process I strived to put my pre-judices into play and use my pre-understandings as a tool to establish a hermeneutic conversation between the participants and me.

7.3. Quality assessment

An important part of a research study is quality assesment. The quality of this study is assessed on the basis of the concepts of reliability and validity. The assessment criteria for reliability and validity in qualitative research are different from those used to establish quality in a quantitative study [134,135]. As an example, reliability in quantitative research refers to exact replicability of the research process and its results [135]. This criterion does not make sense in a qualitative study. Here, the exact same results are impossible to replicate as the researcher closely engages with the participants and forms part of the interpretative process. In the following section, reliability and validity are assessed using the concetps of credibility, transferability, dependability and confirmability as defined by Guba [136].

Credibility
The quality of the results, conclusions and recommendations of a research study are related to credibility, which pertains to the aspect of truth-value [136]. A way to establish truth-value is by testing the credibility of findings and interpretations with the various sources (participants) from which data were drawn. The testing of credibility is often referred to as doing 'member checks'. Member checks is a strategy used with the intension of finding out whether the reality of the participants is captured when data is analysed and interpreted [49]. In the study, member checks were somewhat used. In phase 2, the participants validated results and conclusions from phase 1 through dialogue and collaborative activities. The member checks did not serve the goal of confirming a fixed truth accounted for by me as the researcher. Rather, member checks were used to make sure that the co-design process was directed in a way that mirrored the participant´s problems, needs and preferences.

Triangulation is a strategy to increase credibility [49]. Triangulation is when data sources, different investigators, different perspectives (theories), and different methods are pitted against one another in order to cross-check data and interpretations [136].

Method triangulation is an approach where multiple methods of data collection are employed to investigate the same phenomenon [49,137]. The approach is used to generate a rigorous dataset as the basis for analysis, interpretations, conclusions and recommendations. Method triangulation was used in the study by combining participant observations, interviews, co-design workshops and intervention to investigate, describe and discuss the possibilities of smartphone-based care for young adults with schizophrenia, from different angles.

Investigator triangulation is an approach where two or more researchers participate in the same study to provide multiple observations and conclusions. The approach can bring both confirmation of findings and different perspectives, adding breath to the phenomenon of interest [137]. Investigator triangulation was somewhat used in the study, as data was collaboratively interpreted with my supervisors. I was the only researcher in the study collecting data; hence, investigator triangulation in terms of several researchers in the data collection process as observers or interviewers was not used. Likely, this could have increased the credibility of results and conclusions by establishing a more solid basis for discussions and reflections.

Theory triangulation is an approach where different theories and hypotheses are used to analyse and interpret data. This approach can assist the researcher in supporting or refusing findings [137]. Theory triangulation was used in the study, where hypothesis generated from the data material, from theories and from my pre-understating's and pre-judices were constantly put into play to open up texts (data sources) and to move my horizon. Theory triangulation was not used in order for me to move away from the subject matter under investigation. Rather, it was used to enter the circle of interpretation and establish hermeneutic conversation in the process of moving between parts and the whole.

Data source triangulation is an approach where data is collected from different types of people, including individuals, groups, families and communities to gain multiple perspectives and to validation of the data [137]. Data source triangulation was somewhat used in the study, where data was collected from young adults alone (phase 1 and 3) and together (phase 2) and from HCPs (phase 1 and 2).
The perspectives of families were not sought in the research. Neither were the HCP perspectives on the use and usefulness of the technology. Both perspectives could have provided important insights for the results, conclusions and recommendations of this study.

Transferability

An important quality criterion in a qualitative research study is transferability [136]. The criterion, which is also referred to as pragmatic validity [84,138], pertains to the aspect of applicability or the extent to which the study findings can be extrapolated to populations other than the study population [84]. Transferability can be increased by a means of rich description, as this enables the reader to make their own judgement about whether the work is potentially transferrable to their own contexts, settings and situations. In the study, descriptions of the setting in which the study was rooted, sampling procedures and characteristics of the participants were provided.

An important aspect of the transferability of findings in a research study is the sample population [49]. In all three phases of the study the majority of the participants were women. First episode schizophrenia incident rates are approximately two times higher in men than women [29,139], which made the sample in all phases of the study gender biased. This might indicate that the findings are in favour of women, and that the findings should be transferred with caution. However, so differences were observed between the male and female perception of the support needs, the role as co-designers or the use and usefulness of the technology.

Another thing that might affect transferability is the cultural setting of a study [49]. The study was conducted in one OPUS clinic in Denmark, and included only ethnic Danes. Thereby, the findings reflect the culture, norms and values of young ethnic Danes, in a specific clinic at a specific time. Hence, the findings may not be generalizable to more diverse populations of young adults with schizophrenia. A variation in ethnicity in the sampling procedure might have broadened the understanding in relation to needs of support, the role as co-designers or the use and perceived usefulness of the technology.

An aspect of transferability pertains to the usefulness of study findings. Malterud states that without usefulness, the validity of science is restricted to a space in the outcast of reality. Therefore, transferability should be assessed following a research study to see if and how the produced knowledge has been used [140]. In ensuring transferability, the technology was tested in clinical practice. This provided insights on its use and usefulness. Malterud argues that transferability also should be considered at the start of a research study to determine whether questions have already been addressed and if new answers have any practical consequences [140]. This was assessed when the research was initiated by obtaining literature regarding previous research on smartphone-based care of young adults diagnosed with schizophrenia. The review showed that only few studies had been conducted, and none specifically on the target population. This provided a pragmatic rationale for the study.

Unlike a quantitative study, the intent of a qualitative study is not to claim generalizability of the findings, but a quality parameter for generalization in a qualitative study is analytical generalization [84]. Analytical generalization is based on a theoretical understanding of a phenomena, and emerges by means of the movement between theory and practice [84]. In this study, the empirically generated data was brought into dialogue along with the theoretical preconceptions and theory explored during the research process. Analytical generalization presupposes a detailed description of the research process, in order to make all steps transparent. The findings section and the original papers intended to do so by providing rich descriptions.

Confirmability

Another important quality criterion in a qualitative research study is confirmability, which pertains to the aspect of neutrality [136]. In a qualitative research study neither the researcher, nor the research itself is neutral. Therefore, the researcher must explicate pre-understandings and pre-judices and discuss these in relation to the research process [137].

When the study was initiated I had experiences as a clinical nurse and a researcher within the field of young adults schizophrenia care [110,111]. Therefore, exploring my pre-understandings and pre-judices was vital. The process made me aware that my background in mental health nursing could blindfold me, inhibit frank discussions and thereby increase the risk of reproducing common sense knowledge. These insights were used to stay open and humble toward things still not understood when collecting, analysing and interpreting data. An aspect that might have impacted the confirmability of the study is my prolonged relationship with the participants who proceeded from phase 1 into phase 2. Over the course of time relationships developed, and I grew to become a member of the design team more than a leader of the team. One might argue that the quality of the study thereby was compromised. Reflected in the findings, however, the change of role seemed valuable to the construction of a lingered environment for design, hence something worth striving for in future co-design projects.

Dependability

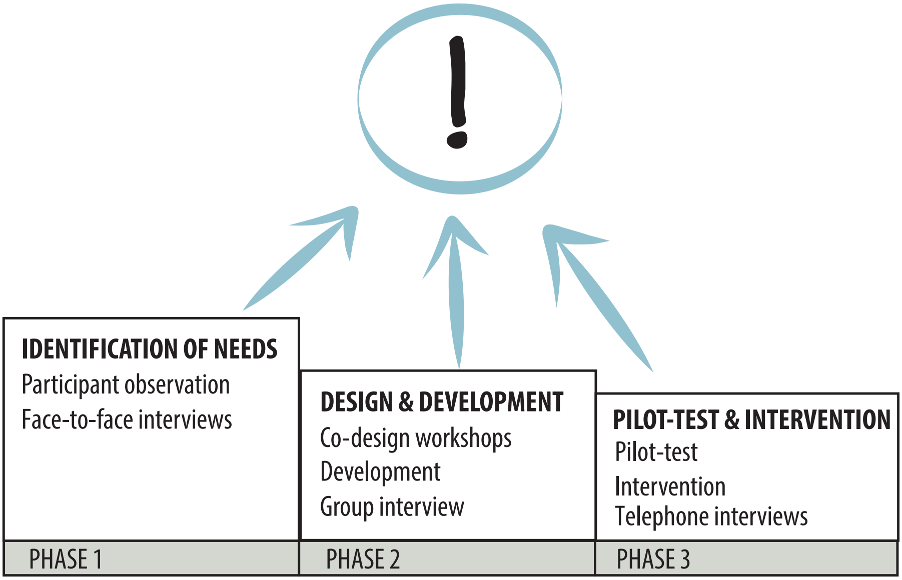
Yet another important quality criterion in a qualitative research study is dependability, which pertains to the aspect of consistency and stringency shown through the presentation of the study [136]. In ensuring dependability agreement between the literature review, the aims, the objectives, the research questions, the methods, the analysis, the interpretations and the conclusions were sought, and steps taken in this respect were shared, to allow the reader to follow my decision making process.

The accuracy of transcripts and translations is a factor of importance for the consistency of a qualitative study [49]. Therefore, transcripts of interviews were created straight after they were conducted, when they were still fresh in mind. To ensure that the interview text would stand as close to what was said as possible, limited punctuation was used and distinct pauses to thoughts like silence, aaaaa of hmmmmm were marked. Since the study was conducted in Danish, and reported in English the translation posed a challenge to trustworthiness [141]. Therefore, analysis of the interviews was conducted in Danish before translating the quotations into English. Translation fidelity was sought in discussions with research colleagues that were native speakers. Likely, a forward-backward translation [141] between Danish and English, could have further improved the translation fidelity.

The consistency of a study highly depends on whether the analytical strategy is well prepared and well documented. The analytical strategy was inspired by Gadamer's philosophical hermeneutics. The strength of a hermeneutic inquiry to data analysis is that it moves between parts and the whole of the text, thereby ensuring depth and accuracy of the interpretations. The process of analysis from raw data to deconstruction of the text and to reconstructing of the text in categories of synthesised meaning, were rendered visible by exemplifying how the analytical levels were performed. Quotations from the interviews were used to make connections to the participant's original statements. As such the process of analysis was shared with the reader, which gives credibility and validity to interpretations [84]. The process is visualised in paper I-III.

CHAPTER 8. CONCLUSION

In this chapter the conclusions of the study is provided in regards to the study aims and objectives.



8.1. Conclusions

This study contributes with knowledge and perspectives to the sparse research base on smartphone-based care of young adults with a recent diagnosis of schizophrenia. The study also contributes with knowledge on the contribution of PD thinking and tools as a means to engage young adults diagnosed with schizophrenia to participate and engage in the design of a smartphone technology meeting their needs of support. Based on the study findings, it is concluded that:

- Smartphone-based care has the potential to support young adults recently diagnosed with schizophrenia to confidently manage everyday living with the illness. This, however, requires of the young adults to monitor the mental health for more than a month and to use the technology closely with the HCP.

- Smartphone-based care may disempower some from feeling certain and secure. Therefore, it should be used individually, in a reflected manner and at the right time in the course of care. This requires that young adults with schizophrenia and their HCP collaboratively and continually evaluate how the care is affecting them.

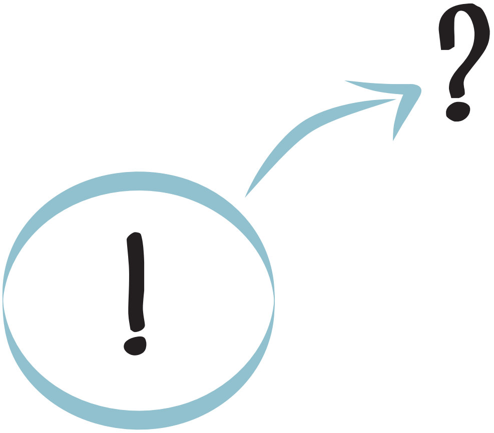
- Smartphone-based care has its restrictions and does not appeal to all young adults with a recent diagnosis of schizophrenia. Studying young adults who have recently been diagnosed with schizophrenia, but who opt out of using technology as a part of their care when it is offered, could help explain this.

- HCPs are crucial for the successful implementation of smartphone-based care among young adults with a recent diagnosis of schizophrenia. Therefore, future research should look into their reservations about its use.

- PD thinking and tools can inspire and support participation and engagement in the development of smartphone-based care with young adults with schizophrenia, given that the environment in which PD unfolds is transparent, flexible, safe and informal. In addition, PD can strengthen the perception of value and worth, thereby promoting personal power. Future research is highly recommended to look into the potential of PD principles and thinking to support young adults diagnosed with schizophrenia on the journey towards mental health recovery.

CHAPTER 9. IMPLICATIONS AND PERSPECTIVES

In this chapter implications of the research findings are shared and perspectives are provided.



9.1. Implications and perspectives

Over the past decade, there has been a paradigm shift in the management of schizophrenia, with an increased focus on early identification and intervention [142]. As part of this paradigm shift, an increased emphasis has been paid to mHealth interventions in the earliest phases of the illness [106,118,143]. This study adds to the novel research base on mHealth as part of early phase schizophrenia care by identifying needs of support in the everyday management of living with schizophrenia, designing and developing a smartphone-based technology to accommodate the needs and by testing the technology in the context of everyday living.

The study highlights that smartphone-based care of young adults recently diagnosed with schizophrenia is viable and underlines the clinical importance of the smartphone as a mode of service delivery to foster power and self-management. Yet, the study underlines that use of the smartphone can disempower the sense of certainty and security. The findings encourages implementation of smartphone-based care into the ambulant care regime of young adults, yet reminds, that it has its limitations, and should continually be evaluated when implemented into the ambulant care setting.

The study shows that PD tools and thinking is a feasible way to engage young adults with schizophrenia to become strong partners in co-designing care responsive to their problems, needs and preferences. The study also shows that PD is efficient to foster personal growth. The findings highlight the benefits of using PD methodology with young adults with schizophrenia, and encourage future research to look into its potentials as a design practice, but also an emancipatory practice, within the broader field of mental health care.

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Appendices

Appendix A: Updated literature search on studies on smartphone use in young adult schizophrenia care

Author, year & app name	Aim(s)	Methods	Findings
Palmier-Claus et al. 2012, ClinTouch [35]	To assess the feasibility and validity of ambulatory self-report of psychotic symptoms using a smartphone software application [35].	Individuals with psychosis were prompted at six pseudo-random times, each day, for seven days to assess key psychotic symptoms using the ClinTouch app. They were prospectively recruited into 3 group: acute, remitted and ultra high risk 'prodromal'. Recruitment continued until each group contained 12 subjects who had managed to complete at least 33% (defined as compliance) of the 42 data points possible. Feasibly and validity was assessed using clinician rated symptom scores and self-reported health data.	Compliance was 82% (36/44). In the 36 compliant participants 5 items (delusions, hallucinations, suspiciousness, anxiety and hopelessness) showed moderate to strong associations with corresponding items from interview rating scales. Four items showed no significant correlation with rating scales: each was an item based on observable behavior. Ambulant ratings showed excellent test-retest reliability and sensitivity to change [35].
Ainsworth et al. 2013, ClinTouch [36]	To compare two different delivery modalities of the same diagnostic assessment for individuals with non-affective psychosis – a native smartphone app employing a graphical touch user interface against an SMS text-only implementation [144].	Using a randomized repeated measure cross over design a sample of community-based individuals with currently treated schizophrenia (n=22) or schizoaffective disorder (n=2) were randomly allocated to completing 6 consecutive days of assesments (4 sets of questions per day at pseudo random times) with ClinTouch or an SMS text-only implementation. To reduce carry over effects a seven days rest period were held between using modality 1 and modality 2. Quantitative feedback questionnaires administred at	A greater proportion of data points were completed with the native smartphone application in comparison to the SMS text-only implementation, and it took significantly less time to complete. There were no significant differences in participants' quantitative feedback for the two delivery modalities, yet, most (67%; n=16) reported preferring the native smartphone application and found it easier to use (71%; n=16). 33% of the participants reported that they would be willing to complete mobile phone assessment for 5 weeks or longer [144].

		the end of each period of sampling to assess the acceptability and feasibility of the two delivery modalities.	
Palmier-Claus et al. 2013, ClinTouch [15]	To understand patient's perceptions of mobile phone based assessment systems and how they may be implemented into everyday routine and clinical practice [15].	Using qualitative interviews a sample of 24 individuals with schizophrenia (see above) were interviewed about perceived use of mobile based assesement and its use in eveyday routine and clinical practice.	In general participants found ClinTouch non-stigmatizing and well integrated into their everyday activities. Yet, the repetitiveness of questions to assess was deemed a likely barrier to long-term adoption. Potential benefits to the quality of care received using ClinTouch were seen in terms of assisting clinicians, faster and more efficient data exchange, and aiding patient-clinician communication. However, participants often failed to see the relevance of ClinTouch to their personal situations, and emphasized the threat to the person-centered element of their care [15].
Ben-Zeev et al. 2016, Cross-Check [33]	To examine the feasibility, acceptability, and utility of behavioural sensing in individuals with schizophrenia [33].	A sample of 9 outpatients and 11 inpatients with schizophrenia (60%) and schizoaffective disorder (40%) recently discharged from hospital carried smartphones for two or one-week periods, respectively. Device-embedded sensors in Crosscheck collected behavioural and contextual data. Participants completed usability and acceptability measures for rating approach [33].	Sensing successfully captured individuals' activity, time spent proximal to human speech, and time spent in various locations. Participants felt comfortable using the sensing system (95%), and most were interested in receiving feedback (65%) and suggestions (65%). Approximately 20% reported that sensing made them upset. One-third of inpatients were concerned about their privacy, but no outpatients expressed this concern [33].

Ben-Zeev et al. 2017, CrossCheck [144]	To describe and demonstrate CrossCheck: a multimodal data collection system designed to aid in continuous remote monitoring and identification of subjective and objective indicators of psychotic relapse [145].	Five data sets (4 female, one male with schizophrenia, age range 19-35 years) were curated from CrossCheck arm of RCT study. Cases chosen because of psychiatric hospitalization in study period. Analysis of sensor data and self-reported data presented for each case [145].	Unique digital indicators of psychotic relapse were identified in the participants. For some, self-reports provided clear and potentially actionable description of symptom exacerbation prior to hospitalization. Others had tends in behavioral sensing or device use patterns that reflected the changes they experienced [145].
Wang et al. 2016, CrossCheck [31]	To present initial results from an on-going randomized controlled study (RCT) on passive monitoring of mental health indicators towards relapse prediction and early intervention in people with schizophrenia [31].	A sample of 21 individuals with schizophrenia recently discharged from hospital carry a phone with the CrossCheck app for up to 12 months. Data indicative to psychotic relapse are sampled by sensors in the app. Data is used to build inference models capable of accurately predicting aggregated scores of mental health relapse indicators in schizophrenia (mean error of 7.6% of the score range) [31].	The predicted mental health indicators strongly correlate with ground-truth. The predictive power of participants' data decreased when temporally more distant data were included in the training of the models. This could be countered by predicting underlying lower frequency trends instead [31].
Ben-Zeev et al. 2014, FOCUS [123]	To assess the feasibility, acceptability and preliminary efficiency of a smartphone intervention for schizophrenia [123].	A sample of 33 individuals with schizophrenia and schizoaffective disorder, mean age (SD) 45.9 (8.78), used FOCUS for one month to facilitate symptom management, mood regulation, medication adherence, social functioning and improved sleep. A battery of laboratory based self-report and interview measures that included demographic information, measures of symptoms of schizophrenia (PANSS), symptoms of depression (BDI-2), and	Participants were able to use FOCUS independently. On average they engaged with FOCUS for 86,5% of the days they had the mobile phone, and 5.2 times a day. They initiated 62% of FOCUS use, and 38% of use were in response to automated prompts. Baseline levels of cognitive functioning, negative symptoms, persecutory ideation, and reading level were not related to FOCUS use. 90% of participants rated the intervention as highly ac-

		sleep difficulties (ISI) was used to establish feasibility, acceptability and efficiency [123].	ceptable and usable. Paired samples t tests found significant reductions in psychotic symptoms, depression, and general psychopathology, after 1 month of use [123].
Ben-Zeev et al. 2016, FOCUS [145]	To evaluate the viability of extended mHealth interventions for people with schizophrenia-spectrum disorders following hospital discharge [146].	A sample of 342 individuals with schizophrenia spectrum disorders, mean age (SD) 35 (11), were given the FOCUS mobile phone intervention (see above) as part of a technology-assisted relapse prevention program during the 6-month high-risk period following hospitalization. FOCUS use “events” were logged automatically by the mobile phone. Engagement outcomes were calculated for each individual. [146]	On average, participants engaged with FOCUS for 82% of the weeks they had the mobile phone. Those who used FOCUS more often continued using it over longer periods. Gender, race, age, and number of past psychiatric hospitalizations were associated with engagement. Females used FOCUS on average 0.4 more days a week than males. White participants engaged on average 0.7 days more a week than African-Americans and responded to prompts on 0.7 days more a week than Hispanic participants. Younger participants (age 18-29) had 0.4 fewer days of on-demand use a week than individuals who were 30-45 years old and 0.5 fewer days a week than older participants (age 46-60). Participants with fewer past hospitalizations (1-6) engaged on average 0.2 more days a week than those with seven or more [146].

Appendix B: Application of the UIM tool in the study

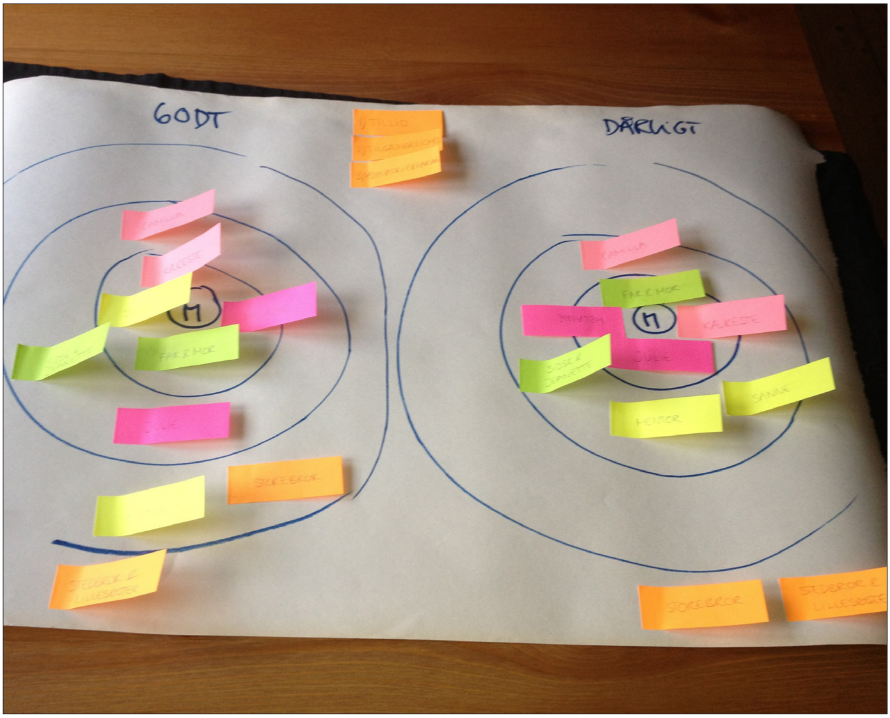
UIM steps	UIM themes	UIM preparations
Co-operation	**Select**	Aim: To select participants Who participate: Young adults recently diagnosed with schizophrenia and HCPs Allocation: OPUS How: Information letter about project and invitation for participation
	Plan	Aim: To plan cooperation How: Meetings with OPUS staff, designers and graphic facilitator Where: OPUS, Trifork, ProcessInk Outcome: Plan of action
Context	**Insights**	Aim: To generate insight into problems and needs How: Participant observations and face to face interviews Who's insights: Young adults Outcome: Direction for design
	Vision	Aim: To generate visions for possible futures of support Who's visions: Young adults and HCPs How: Co-design workshops Outcome: Ideas for using the smartphone for support
Concept	**Sketch**	Aim: To sketch ideas for smartphone based support How: Co-design workshops Who sketch: Young adults, HCP's and designers Outcome: A requirement specification for the development of the technology
	Present	Aim: To present the concept for smartphone based support How: Co-design workshops Who present: Designer and me Who participate: Young adults and HCPs Where: OPUS Outcome: Specification of adjustment of technology

Appendix C: Interview guide to identify needs and generate ideas (Danish)

Temaer	Rammesætning	Spørgsmål og hjælpespørgsmål
Intro	Endnu engang tak fordi du vil deltage i interviewet. Interviewet er bygget op omkring tre temaer. Som jeg nævnte tidligere svarer du kun på et du har lyst til og der er ingen rigtige eller forkerte svar. Inden vi går i gang vil jeg høre om du har nogle spørgsmål?	
Udfordringer i dagligdagen	Jeg vil gerne starte med at tale med dig om din dagligdag og de eventuelle udfordringer du oplever i dit daglige liv med din sygdom.	• Kan du beskrive hvordan en typisk dag ser ud fra du står op om morgenen til du går i seng om aftenen? • Hvad laver du? • Hvem er du sammen med? • Er der ting i din dagligdag som du har brug for hjælp til? • Hvilke? • Hvorfor? • Hvor ofte?
Den gode hjælp til at mestre dagligdagen	Det næste jeg gerne vil tale med dig er om er 'hjælp der hjælper' altså den hjælp der for dig er vigtig for bedst at kunne håndtere din dagligdag med sygdommen. For at få et billede af, hvem der hjælper dig, vil jeg gerne undersøge sammen med dig hvem dit netværk består af, og hvilken rolle disse personer har i og for håndteringen af dit daglige liv med sygdommen. Det kan f.eks. være familie, kolleger, venner, behandlere osv. For at gøre det konkret vil jeg gerne bruge et Venn Diagram, der er en slags netværkskort , og en bunke post-its. På hver post-it	• Kan du beskrive hver person på kortet og hvorfor denne er vigtige for dig? • Hvad er personens vigtigste opgave? • Hvordan hjælper denne person dig? • Hvad gør denne person der er særligt godt? • Hvad gør denne person aldrig? • Hvad måtte denne person gerne gøre mere af/mindre af? • Hvad er din rolle i samarbejdet med denne person? • Hvordan opleves det at få hjælp af denne person? • Hvordan modtager du hjælpen fra denne person? Fx: fysisk? email?

Temaer	Rammesætning	Spørgsmål og hjælpespørgsmål
	skriver du navnene på de personer der er vigtige. Som du kan se består netværkskortet af en række cirkler. Cirklerne er udtryk for, hvor 'vigtige' du oplever de forskellige personer er i håndteringen i og af din sygdom. Logikken er: tæt på centrum meget vigtig. Langt fra centrum = mindre vigtig.	• SMS? telefon opkald? virtuelt netværk? andet?
Smartphone som støtteværkstøj i håndteringen af dagligdagen	Det sidste jeg gerne vil tale med dig om er, hvordan du evt. bruger eller tænker du kunne bruge tænker at en smartphone som støtte i dit daglige liv med din sygdom.	• Har du en telefon? • Bruger du telefonen ift. håndtering af din sygdom? I fald hvordan? Fx. søge viden? kontakt? monitorering? netværk med ligesindede? holde styr på aftaler? finde vej (GPS)? • Bruger du apps til at hjælpe dig med at håndtere din sygdom? Hvilke? og Hvad bruger du dem til? • Hvilke funktioner i en telefon tænker du kunne være en hjælp for dig i håndteringen af dit daglige liv?
Afslutning	Inden vi afslutter vil jeg høre, om der er noget vigtigt, du tænker, vi ikke har været inden omkring? Og så vil jeg lige høre, om det har været ok at deltage? Hvis jeg har yderligere spørgsmål, må jeg så kontakte dig igen? Har du lyst til at blive kontaktet med henblik på eventuel deltagelse i næste del af studiet hvor der designes en smartphone app? Mange tak for din tid og dit bidrag!	

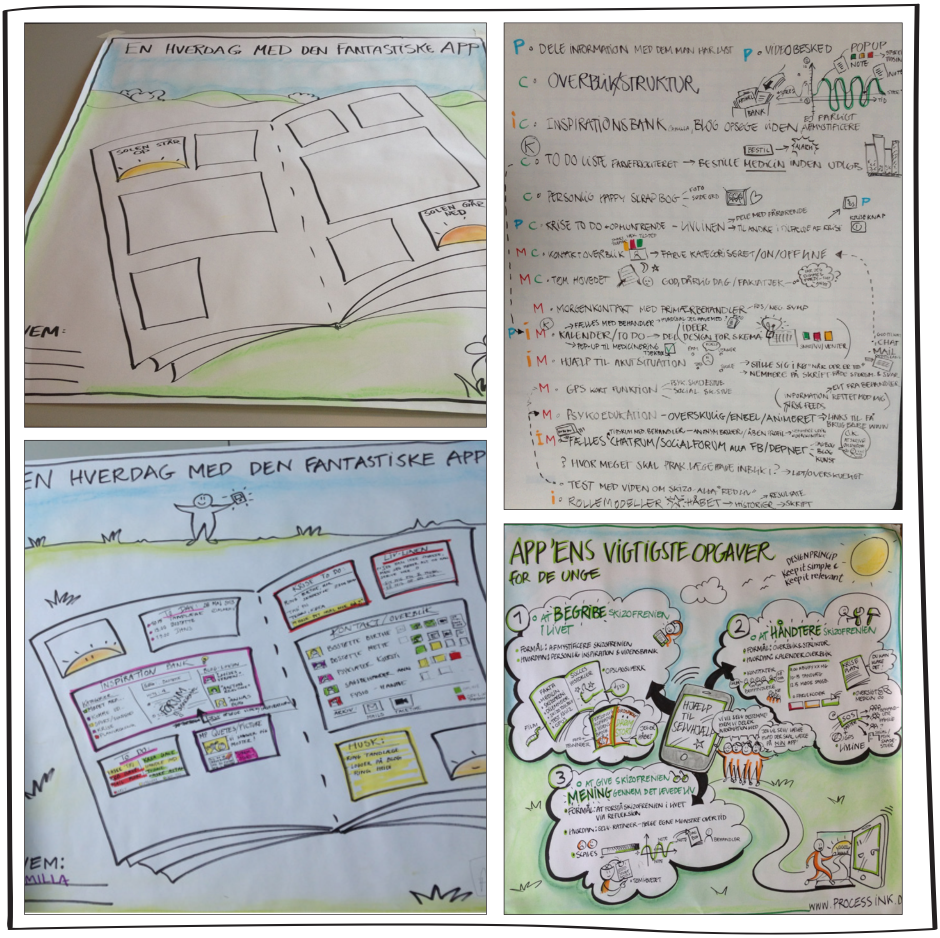
Appendix D: Example of a Venn diagram made by a study participant



The Venn diagram was used with the interviews in phase 1 to address the young adult´s supportive network and the role of the network on good and bad days, respectively. This was in order get an idea of the how the technology should be 'wired' to accommodate their needs of support in everyday life.

Appendix E: Photos of selected tools employed in the workshops

Poster aim and poster agendas were hanging on the wall in the first three workshops to provide overview. The photo collage shows the poster aim, inclusing the mission, design principles and goal and the agendas for workshop 2 and 3 respectively.



In workshop 1 a storyboard designed as a comic book was used to explore 'the good day with the amazing app'. All drew their own story and presented it. The presentation was recorded visually and findings were synthesised. The photo collage shows the storyboard template, an example of a storyboard drawn by a study participant, visual notes of ideas for app resources, and a visual synthesis of the ideas. The synthesis was used to set the direction for subsequent workshops

The ideas for app resources were visualised and posted at the wall in workshop 3. The photo collage shows how post-it notes were used to vote for app functionalities. The young adults and the HCPs had different colours to easily spot differences in their preferences.

Mock-ups designed a big cartoon smartphone interfaces were used to sketch envisioned ideas and stimulate discussions. The mock-ups were used with a design catalogue with fonts, colours, symbols and signs. The photo collage shows examples of ideas mock-up for look and feel of the app and self-monitoring of the mental health state.

Appendix F: Interview guide to evaluate use and perceived usefulness of MindFrame

Introduktion: Mange tak fordi du vil deltage i evalueringen af MindFrame. Formålet med interviewet er, at blive klogere på hvordan systemet er anvendt og hvordan det har været at anvende det. Jeg ønsker derfor både at høre om det der har virket for dig, og det der ikke har virket. Herudover vil jeg gerne tale med dig om hvad du tænker der skulle til, for at MindFrame blev mere anvendelig for andre unge i OPUS behandling.

Deltagerbetingelser: Din deltagelse i interviewet er frivilligt. Det betyder at du på et hvilket som helst tidspunkt, kan trække dit tilsagn om deltagelse tilbage, uden dette får betydning for det videre forløb i klinikken. Som deltager svarer du KUN på det du har lyst til og der er ingen forkerte svar.

Anonymitet: Navne og stednavne tages ud af dokumentet. Det betyder, at udenforstående ikke vil genkende dig som person i det færdige materiale.

Båndoptagelse: Interviewet forventes at tage mellem 30-45 minutter og bliver optaget på bånd. Efterfølgende skrives det ordret til et samlet dokument og båndoptagelsen slettes. Båndoptagelsen tjener alene til formål, at jeg bagefter kan huske hvad vi talte om.

Anvendelse: Interviewet anvendes som en del af et videnskabeligt materiale på konferencer og i artikler.

Vejledning: Du svarer kun på det du lyst til og der er ingen forkerte svar. Du må meget gerne komme med konkrete eksempler. Afslutningsvis er der en række statements, som jeg gerne vil høre hvad du tænker om.

Samtykke: Før vi starter interviewet, skal jeg høre om du stadig har lyst til at deltage? Og om du har spørgsmål af nogen art? Hvis du er klar, så starter vi.

Temaer	Rammesætning	Spørgsmål og hjælpespørgsmål
Introduktion til MindFrame	Det første jeg gerne vil tale med dig om er din introduktion til MindFrame.	• Hvordan blev du introduceret til MindFrame (MF)? • Hvem? Hvordan? Hvornår i dit forløb? • Hvad husker du fra introduktionen? • Hvad ved MF appellerede til dig • Hvad appellerede ikke til dig? • Lavede du aftaler om brugen af MF med din behandler inden du gik i gang? I fald, hvilke? Fx: Forventet brug, ansvar fordeling forventnings afstemning?
Anvendelse af MindFrame	Det næste jeg gerne vil tale med dig om er, hvordan du har brugt MindFrame.	• Hvordan har du anvendt MF? • Hyppighed (dagligt, gode/dårlige perioder) • Version (telefon, web, begge), Alene/med behandler • Funktioner (selv-evaluering (noter), visualisering, handlingsplaner, triggers, advarselstegn, medicinoverblik)

Temaer	Rammesætning	Spørgsmål og hjælpespørgsmål
Anvendelighed af MindFrame med fokus på power og empowerment	Det næste jeg gerne vil tale med dig om, er din vurdering af, hvorvidt og hvordan MindFrame har haft betydning for håndteringen af din dagligdag med din sygdom.	• Har MF haft betydning for din forståelse af din sygdom? • Hvilke funktioner i MF har hjulpet dig til at forstå din sygdom bedre? Og hvordan? • Er der funktioner i MF der har skabt usikkerhed om din sygdom? Hvorfor? Og Hvordan? • Hvilken rolle har din behandler haft for at øge din forståelse? • Har MindFrame haft betydning for din håndtering af din sygdom i dagligdagen? • Har MF hjulpet dig til bedre at kunne håndtere din sygdom selvstændigt? Hvilke funktioner? Og Hvordan? • Har MF på nogen måde gjort det sværere at håndtere din sygdom? • Hvilken rolle har din behandler haft for at øge din evne til at håndtere din sygdom? • Hvordan vurderer du anvendeligheden af MindFrame i OPUS behandling generelt? • Hvilke fordele og ulemper vil du fremhæve ved at bruge MF? • Er der funktioner i OPUS der kan erstatte noget i dit OPUS forløb i dag? • Hvordan ville du fulende sætningen: Du skal prøve MindFrame fordi den…. • Hvad vurderer du der skulle til, for at MF blev mere anvendelig i OPUS behandling? Fx: indhold (funktioner), teknologisk (stabilitet, opdateringer), overblik (opbygning, brugervenlighed) • Hvordan ville du fuldende sætningen: Hvis jeg skulle bruge MF mere så skulle den have kunnet hjælp mig med…?

Temaer	Rammesætning	Spørgsmål og hjælpespørgsmål
Potentialer ved brug af MindFrame	Det sidste jeg gerne vil, er at høre dine umiddelbare bud på en række spørgsmål omkring fordele og ulemper ved at bruge MF. Fælles for spørgsmålene er at de kan svares med ja eller nej. Muligvis har du allerede været omkring spørgsmålene i det forrige afsnit. Hvis ikke, er du meget velkommen til at komme med uddybende svar.	• Når jeg bruger MF bliver jeg stresset! • Når jeg bruger MF bliver jeg mindre bekymret og mere rolig! • Når jeg bruger MF bliver jeg mere i tvivl om hvad der er rigtigt og forkert! • Når jeg bruger MF er det lettere at forstå mig selv og mit liv! • MF bidrager med håb i mit liv! • Når jeg bruger MF føler jeg mig mere i kontrol! • Når jeg bruger MF føler jeg større ansvar for mig selv og mit liv! • Når jeg bruger MF bliver jeg mere involveret i min behandling! • Når jeg bruger MF er det lettere at tage beslutninger! • Når jeg bruger MF bliver det lettere at passe på mig selv! • Når jeg bruger MF føler jeg mig mere syg! • Når jeg bruger MF føler jeg mig overvåget! • Når jeg bruger MF bliver det lettere at tale med min behandler om det der er svært! • MF har været en hjælp til at få en bedre hjælp! • MF gør min behandling mere upersonlig!
Afslutning	Inden vi afslutter vil jeg høre, om der er noget vigtigt, du tænker, vi ikke har været inden omkring? Og så vil jeg lige høre, om det har været ok at deltage? Hvis jeg har yderligere spørgsmål, må jeg så kontakte dig igen? Mange tak for din tid og dit bidrag!	

Appendix G: Workshop invitation

Kære

Jeg brug for netop din hjælp til at designe Danmarks mest Cool Smart Care app.
App'en skal hjælpe unge med skizofreni med at holde overblik og kurs og blive kaptajn i eget liv.

Jeg håber derfor du har lyst og tid til at blive en del af vores team som består af fire unge med skizofreni, en kaospilot, en grafisk illustrator, en softwareudvikler og en designer.

Vi mødes på Nordkraft tirsdag d. 28 maj fra 9.30-15.

Du skal dele din ekspertviden om livet med skizofreni. Eneste forberedelse til dagen er at overveje, hvilke tre apps der er dine favoritter for tiden og hvorfor.

Har du spørgsmål så ring eller skriv endelig.
Du fanger mig på 40128333 eller m.terp@rn.dk .
senest torsdag d. 21. Maj.

Mange hilsner, Malene

DGI-HUSET I NORDKRAFT
TEGLGÅRDS PLADS 1
9000 AALBORG

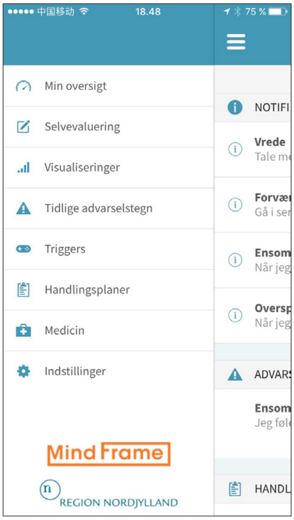
MISSION: at udvikle en nordjysk psykiatri i verdenklasse for unge voksne med skizofreni

HVORDAN: ved at re-designe psykiatrien, så fleksibel hjælp og støtte bliver en mulighed 24/7

HVORFOR: for at gøre det lettere at få den rette hjælp og støtte, når man kommer 'ud af kurs'

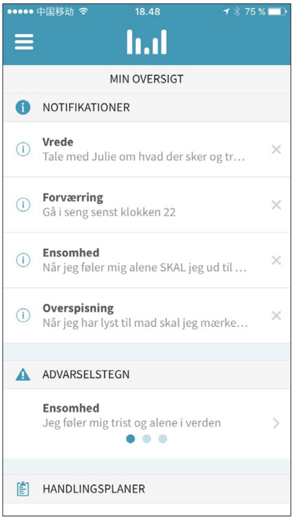
DU KAN FØLGE PROCESSEN MED APP UDVIKLINGEN VIA WWW.SKIZOFRESTIL5.DK

Appendix H: Screenshots of the MindFrame technology



Min oversigt
Selvevaluering
Visualiseringer
Tidlige advarselstegn
Triggers
Handlingsplaner
Medicin
Indstillinger

The MindFrame welcome screen provides an overview of the assessible resources.



MIN OVERSIGT

NOTIFIKATIONER

Vrede
Tale med Julie om hvad der sker og tr…

Forværring
Gå i seng senst klokken 22

Ensomhed
Når jeg føler mig alene SKAL jeg ud til …

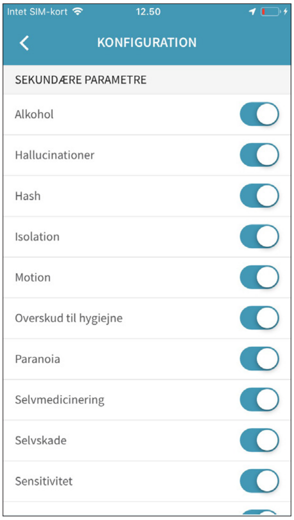
Overspisning
Når jeg har lyst til mad skal jeg mærke…

ADVARSELSTEGN

Ensomhed
Jeg føler mig trist og alene i verden

HANDLINGSPLANER

When the ’my overview’ button is pushed notifications and warnings signs of the individual is displayed and customized plans of actions are provided.

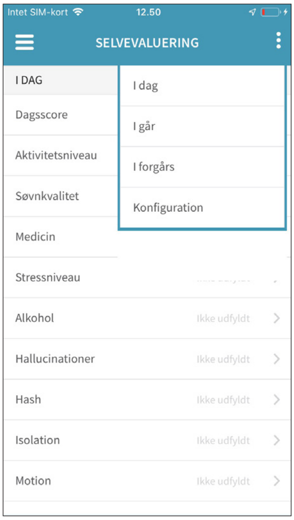


KONFIGURATION

SEKUNDÆRE PARAMETRE

Alkohol
Hallucinationer
Hash
Isolation
Motion
Overskud til hygiejne
Paranoia
Selvmedicinering
Selvskade
Sensitivitet

The app is configured to the user. The screenshot shows some of the optional parameters to add to one´s personal assessment list.



I DAG

Dagsscore

Aktivitetsniveau

Søvnkvalitet

Medicin

Stressniveau

Alkohol Ikke udfyldt

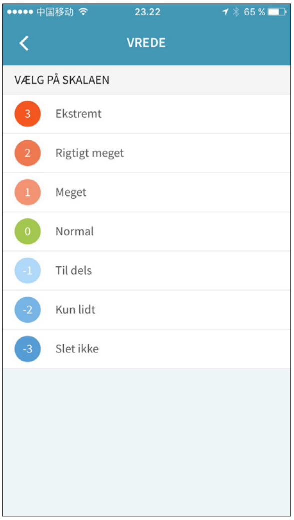
Hallucinationer Ikke udfyldt

Hash Ikke udfyldt

Isolation Ikke udfyldt

Motion Ikke udfyldt

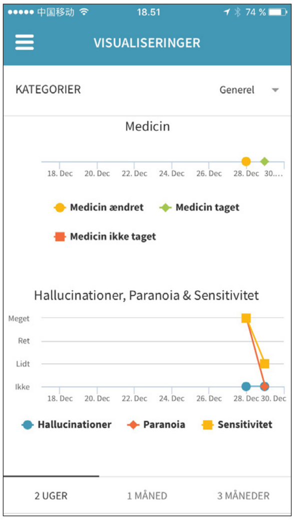
The self-assessment reources enables the user to report the mental health state.



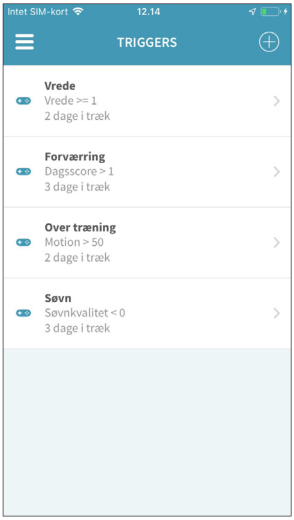
VÆLG PÅ SKALAEN

- 3 Ekstremt
- 2 Rigtigt meget
- 1 Meget
- 0 Normal
- -1 Til dels
- -2 Kun lidt
- -3 Slet ikke

Different scales are used to assess the mental health state. The screenshot shows a 3 to plus 3 scale used for a self-defined parameter (anger).



Data are displayed in the app and shared with the HCPs on the website to support collaboration.



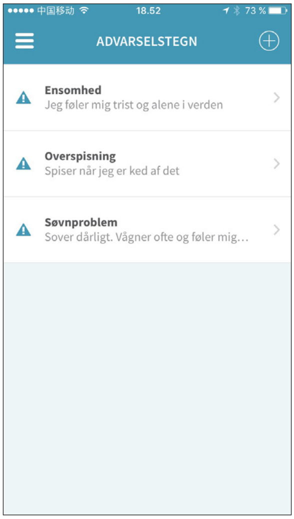
Vrede
Vrede >= 1
2 dage i træk

Forværring
Dagsscore > 1
3 dage i træk

Over træning
Motion > 50
2 dage i træk

Søvn
Søvnkvalitet < 0
3 dage i træk

The trigger and notification resource survey data automatically to notify signs of illness exacerbation and provides feedback on the 'my overview screen' on actions to take to stay well.

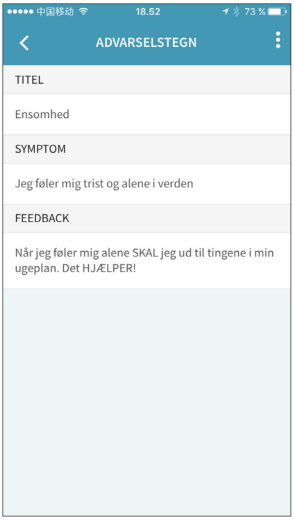


Ensomhed
Jeg føler mig trist og alene i verden

Overspisning
Spiser når jeg er ked af det

Søvnproblem
Sover dårligt. Vågner ofte og føler mig…

The warning sign resource displays signs of illness exacerbation to be aware of and suggestions of how to manage them to stay well.



TITEL

Ensomhed

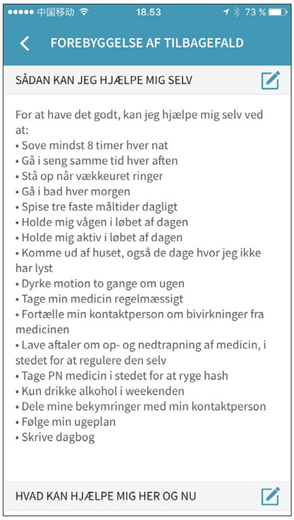
SYMPTOM

Jeg føler mig trist og alene i verden

FEEDBACK

Når jeg føler mig alene SKAL jeg ud til tingene i min ugeplan. Det HJÆLPER!

Example of how to manage the feeling of loneliness.

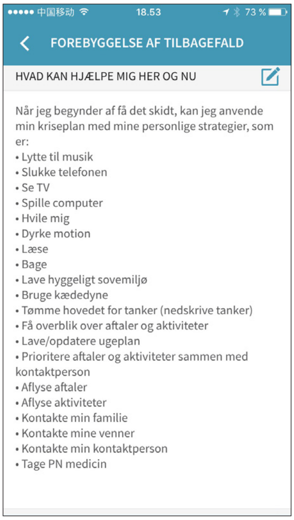


SÅDAN KAN JEG HJÆLPE MIG SELV

For at have det godt, kan jeg hjælpe mig selv ved at:
- Sove mindst 8 timer hver nat
- Gå i seng samme tid hver aften
- Stå op når vækkeuret ringer
- Gå i bad hver morgen
- Spise tre faste måltider dagligt
- Holde mig vågen i løbet af dagen
- Holde mig aktiv i løbet af dagen
- Komme ud af huset, også de dage hvor jeg ikke har lyst
- Dyrke motion to gange om ugen
- Tage min medicin regelmæssigt
- Fortælle min kontaktperson om bivirkninger fra medicinen
- Lave aftaler om op- og nedtrapning af medicin, i stedet for at regulere den selv
- Tage PN medicin i stedet for at ryge hash
- Kun drikke alkohol i weekenden
- Dele mine bekymringer med min kontaktperson
- Følge min ugeplan
- Skrive dagbog

HVAD KAN HJÆLPE MIG HER OG NU

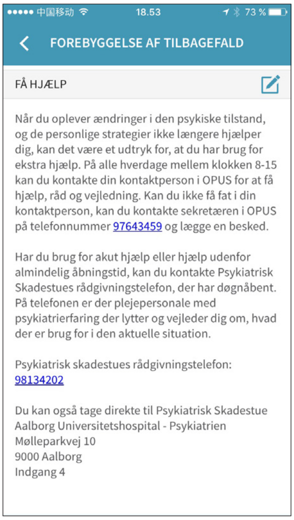
The action plan resource provides stategies to stay in good health. The screenshot shows examples of actions to take to stay well.



HVAD KAN HJÆLPE MIG HER OG NU

Når jeg begynder af få det skidt, kan jeg anvende min kriseplan med mine personlige strategier, som er:
- Lytte til musik
- Slukke telefonen
- Se TV
- Spille computer
- Hvile mig
- Dyrke motion
- Læse
- Bage
- Lave hyggeligt sovemiljø
- Bruge kædedyne
- Tømme hovedet for tanker (nedskrive tanker)
- Få overblik over aftaler og aktiviteter
- Lave/opdatere ugeplan
- Prioritere aftaler og aktiviteter sammen med kontaktperson
- Aflyse aftaler
- Aflyse aktiviteter
- Kontakte min familie
- Kontakte mine venner
- Kontakte min kontaktperson
- Tage PN medicin

The screenshot shows examples of actions to take when the illness exacerbarates.



FÅ HJÆLP

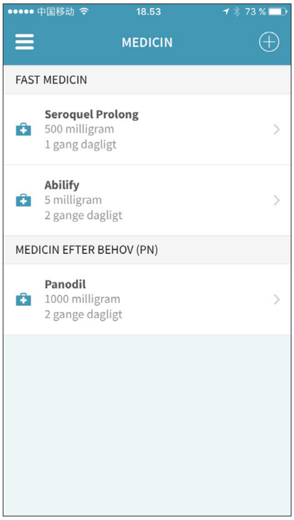
Når du oplever ændringer i den psykiske tilstand, og de personlige strategier ikke længere hjælper dig, kan det være et udtryk for, at du har brug for ekstra hjælp. På alle hverdage mellem klokken 8-15 kan du kontakte din kontaktperson i OPUS for at få hjælp, råd og vejledning. Kan du ikke få fat i din kontaktperson, kan du kontakte sekretæren i OPUS på telefonnummer 97643459 og lægge en besked.

Har du brug for akut hjælp eller hjælp udenfor almindelig åbningstid, kan du kontakte Psykiatrisk Skadestues rådgivningstelefon, der har døgnåbent. På telefonen er der plejepersonale med psykiatrierfaring der lytter og vejleder dig om, hvad der er brug for i den aktuelle situation.

Psykiatrisk skadestues rådgivningstelefon:
98134202

Du kan også tage direkte til Psykiatrisk Skadestue
Aalborg Universitetshospital - Psykiatrien
Mølleparkvej 10
9000 Aalborg
Indgang 4

The screenshot shows actions to take when the stratgeies do not work.



FAST MEDICIN

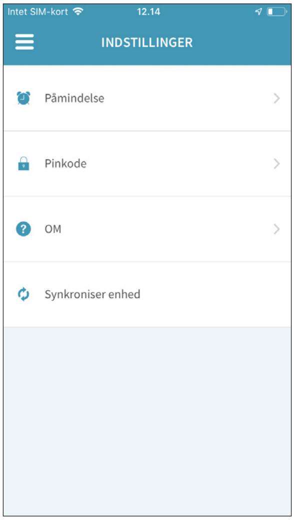
Seroquel Prolong
500 milligram
1 gang dagligt

Abilify
5 milligram
2 gange dagligt

MEDICIN EFTER BEHOV (PN)

Panodil
1000 milligram
2 gange dagligt

The medication resource provides an overview of medication.



The setting resource allows to set up reminders and to change pin-code. It provides access to user-guide and into film.

PAPER I

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Collaborating with Young Adults Diagnosed with Schizophrenia: A Participatory Design Study to Shape the Healthcare System

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Abstract

Introduction: Disengagement from mental health services in young adults with schizophrenia has been associated with dissatisfaction and unmet needs. Striving to improve engagement, we invited service users recently diagnosed with schizophrenia to be co-designers of a smartphone technology that will be responsive to their needs. Aim: This paper reports the first phase of a three-phased participatory design process. The objective was to identify needs of support in young adults recently diagnosed with schizophrenia and to generate ideas of how the needs could be accommodated using smartphone technology. Methods: Participatory design guided the research process and a qualitative approach was used to generate and analyse the data. Data were generated by means of participant observations ($n = 45$ hours) and interviews ($n = 6$) with young adults from a first episode psychosis program in Denmark. Findings: Low levels of knowledge and high levels of uncertainties are characteristic of young adults recently diagnosed with schizophrenia, bringing about a vast need of support in order for them to gain power over their new life situation. Our study suggests that the smartphone may be used to foster empowerment by guiding the young adult's actions in situ, providing comprehensive and easily understood information on the go, allowing for recovery tracking, and notification of mental health changes, providing medication overview and giving easy access to healthcare providers. Conclusion: Young adults recently diagnosed with schizophrenia require comprehensive support in order to become empowered to confidently manage their new life situation. The smartphone holds this potential by offering flexible collaboration and timely access to self-management resources.

Keywords

Empowerment, Mobile Health, Participatory Design, Schizophrenia, Young adults

1. Introduction

The early phases of schizophrenia have gained increased attention over the past decade, and today it is well established that when a young adult suffers from a psychotic illness, intensive care is required to control symptoms, prevent psychotic relapse and improve quality of life [1] [2] [3]. Encouraging and promoting service engagement among young adult in the early phases of schizophrenia, however, is a challenge despite intensive and specialized care being routinely offered [4] [5] [6]. This is a serious treat to mental health recovery, as disengagement, when a service is still needed, can lead to devastating consequences [7], including exacerbations of psychotic symptoms [8] [9] social isolation and suicidal behaviour [3].

It is hypothesized that the first five years of schizophrenia care is optimal to change the long-term course of the illness [3]. Fostering service engagement in the early phases of schizophrenia therefore is of particular importance to improve the mental health recovery.

Research has been established that disengagement from mental health services is associated with dissatisfaction [5] and unmet needs [6] in persons with schizophrenia. This provides a strong basis for shaping services around input from service users, which would then foster mental health recovery through healthcare that they themselves perceive to be meaningful and relevant.

Shaping services with mental health users, however, is not common practice [10]. This is true regardless of user-involvement being at the heart of the recommendations for a more modern and sustainable mental healthcare system [10] [11] [12] [13] [14], and irrespective of research designating that service user involvement offers a promising pathway towards better quality healthcare, more efficient care and improved population health [15] [16] [17].

As a result, we set out to shape an early intervention service in collaboration with young adults recently diagnosed with schizophrenia. We wanted to design a service that was "engaging", by grounding the innovation in user needs and by drawing on the power of smartphone technology to extend services beyond the confines of the physical clinic [18] [19] [20]. Smartphone ownership is particularly high in younger people with schizophrenia [21] making the smartphone highly relevant as a tool to respond to service user needs at all times.

This article reports the first phase of a three-phased participatory design process. The objective of the first phase was to identify the needs of support in young adults recently diagnosed with schizophrenia, and to generate ideas of how the needs could be accommodated using smartphone technology. The objective of phase two and three were to design and develop the technology and to test it in a clinical setting, respectively.

Figure 1 provides an overview of the different phases and activities in the participatory process of shaping, designing and testing a service with young adults recently diagnosed with schizophrenia.

2. Methods

2.1. Research Design

The overall research was conducted within a methodological framework of participatory design (PD) [22]. PD has roots in action research [23], and is preoccupied with finding and developing solutions to practical problems in close collaboration with service users [24] [25] [26] [27]. Therefore, PD supports the practice of making service users co-designers of services responsive to their needs.

A qualitative approach was used to generate and analyse the data. In the first phase of the PD process, data were collected through participant observations and interviews with service users from a specialized first episode psychosis program in Denmark (OPUS). OPUS is a two-year program that provides intensive care for young adults between the ages of 18 - 34 years old, recently diagnosed with schizophrenia. Participant observations were carried out to generate a contextual understanding of the young adults' problems and needs, in order to get a grasp of what mattered most to them. Observations were primarily used to identify themes for a semi structured interview guide [28], thus, the findings in this article solely focus on the interviews.

2.2. Participants and Data Collection

Firstly, the first author carried out passive participant observations (45 hours) to construct the interview guide. The observations were obtained in the primary contexts of the OPUS program. This included an outpatient clinic in which home consultations were provided as well as an in-patient clinic for young adults only. Observations and field notes were taken concurrently in accordance with Spradleys recommendations [29]. Nine observations of home visits, with two nurses and an occupational therapist, were obtained. The rest of the time was spent in the car or the clinic talking to healthcare professionals (HCPs) about the problems of living with schizophrenia and the needs to be accommo-

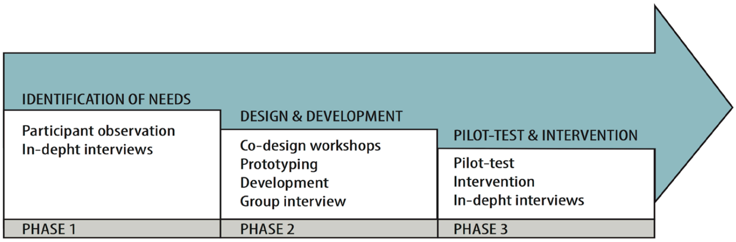

Figure 1. An overview of the different phases and activities in the participatory design process.

dated. The managers of both settings gave their consent to be observed, and patients were asked permission for the first-author to sit in on conversations between them and their HCP.

Secondly, the first author conducted individual interviews with (n = 6) young adults from the OPUS program, using the interview guide. In order to encourage the participants to speak freely, interview questions were open ended and not established in a fixed sequence, rather as prompts [30]. A Venn diagram [31] was used as a tangible artefact to address the supportive network, in an attempt to get an idea of how the technology should be "wired" to accommodate the needs of the young adults in a real life setting. To secure depth of data, each interview was continued until saturation had been reached [32], therefore, the interviews stopped when the narrative became repetitive and no new data were revealed. Interviews lasted between 55 minutes to 1 hour and 18 minutes. They were conducted either at the participants' home (5 interviews) or at the research unit at the hospital (1 interview) depending on participant's preference. Interviews were digitally recorded and transcribed verbatim. The interviews were conducted in Danish; therefore the quotes in the findings section were translated into English, omitting any corrections in phrasing.

Criteria for inclusion in the study were willingness and ability to share information and ideas by virtue of knowledge and experience. However, since it has been argued that individuals who are not "stuck" with too much experience make excellent innovators [33] [34], we were interested in recruiting participants that had been diagnosed within the past year. Criteria for exclusion were inability to speak or understand Danish and unwillingness to provide written consent. Recruitment was conducted in close collaboration with HCPs from OPUS, who singled out relevant participants, gave them an information letter and asked them to consider participation. The first-author contacted them either by phone or email, to make further arrangements, when consent had been obtained.

2.3. Data Analysis

A hermeneutical approach to data analysis was chosen. Within this frame of reference, interpretation of meaning is an iterative and circular process [35], which fits the methodology of PD [36]. In the tradition of Gadamer it is rejected, that hermeneutics is a step-by-step method, rather it is an explication of general principles [28]. Guided by canon principles of hermeneutical interpretation, interpretation of meaning was constructed through an incessant back-and forth process between parts and the whole of the interview text, which follows from the hermeneutical circle. The process of hermeneutical questioning continued until an inner unity of a text free of logical contradictions had been reached.

2.4. Ethical Considerations

The study was submitted to the North Denmark Region Committee on Health Research Ethics. In accordance with Danish law, the committee found that a formal ethics approval of the study was not required. In line with the Helsinki

Declaration [37], all participants were fully informed about the purpose of the study and informed consent was obtained both verbally and in writing before enrolment. The participants retained the right to withdraw from the study at any given point, and they were carefully informed, that withdrawal would not influence their course of care. Authorization by the Danish Data Protection Agency was obtained (2008-58-0028).

3. Findings

Six participants in the OPUS program were eligible for interviews (four women, two men). All accepted the invitation to participate. At inclusion, the age of the participants ranged between 19 - 27 years. All had been diagnosed within the past year, received social benefits and lived independently. All owned a mobile phone and used it on a daily basis.

The hermeneutical inspired process of analysis governing the findings is outlined in **Figure 2**. Based on the young adults descriptions of living with schizophrenia, we identified a need of support to gain power, to be able to control the new life-situation confidently. The need was related to low levels of knowledge and high levels of uncertainties, making the new and changed life situation somewhat impossible to cope with independently. Six ideas for resources to accommodate the need using smartphone technology were identified. The findings are outlined in the next section.

Interview text Quotations	Immediate answers: What is said in relation to needs?	De-contextualisation through interpretation	Result: Needs of support arise from the coding process	Ideas to accommodate the needs of support
"...would be really nice to get suggestions for how to help myself [...] and to have the suggestions handy"	Suggestions for how to help myself Have the suggestions handy	Request for power to self-manage illness on side	Support to take actions in-situ	In-situ guidance
"I often forget, how I was yesterday [...] it feels as though the good days calmly passes by"	Often forget Good days passes by	Impaired memory makes progress hard to recall	Support to recall own process of recovery	Recovery tracking
"Often I do not understand what is going on [...] really stressful not knowing what to expect from the illness"	Do not understand Stressful not knowing what to expect	Powerless in 'reading' the illness	Support to identify deterioration	Notifications of illness exacerbation
"Its really difficult to remember all the different drugs I have tried the past year [...] a whole lot easier if I had some sort of chart at hand that I could show them"	Difficult to remember Easier if I had some sort of chart at hand that I could show them	Request for help to keep overview of medication	Support to recall past and present drugs at all times	Wired list of medication
"I searched the Internet for facts about the illness, just to know what I should expect"	Search the Internet for facts What I should expect	Internet as source to get timely information	Comprehensive info around the clock	On demand information
"I´m so happy that she [the nurse] has a mobile phone. She is always within reach. That is really comforting to know"	Mobile phone Always within reach Comforting	Availability increase sense of certainty	Boundless and 'out of hours' communication with health care providers	Online lifeline

Figure 2. Outline of the hermeneutical process of analysis governing the study findings.

3.1. A Need of Support to Gain Power in Order to Control the New Life Situation Confidently

3.1.1. *In-Situ* Guidance

The participants emphasized how they sometimes felt powerless and helpless in managing the illness and their new life situation. All had received psychoeducation, either only individually or individually followed by 10 weeks of group sessions with other service users in the OPUS program. The participants were explicit that education about the nature of the illness, recovery rates, medication, relapse prevention and symptom management was truly helpful, and key to becoming in charge of the illness, rather than a victim of it:

"*What has helped me the most has been to learn about the illness. When I began to know the signs* [*of illness*] *and know when I was extra vulnerable, I got power. Then I was smarter than my own head. There could be just as many questions and concerns, but because I had seen through it* [*illness*], *then I could do something in advance-I could act instead of just being a victim*."

However, despite their contentment with the psychoeducation, in specific situations they felt incapable of translating the knowledge obtained in the "classroom" into action. Lack of "translation" and "adoption" skills made them reliant on help from their HCPs. Nevertheless, dependency was something the participants strived to extricate themselves from, and they stressed the need of having access to resources, that could guide them "in situ" to self-manage the illness appropriately and pro-actively:

"*It would be really nice to get suggestions for how to help myself… and to have the suggestions handy. Then it would be a whole lot easier to manage this in the long run*."

Thus, it appeared that extending psychoeducation outside the physical walls of the classroom was crucial for making the young adults more independent and increasing their confidence in their ability to navigate their new life situation. This became especially visible in regard to the time restriction of the OPUS program. Since the program was within a two-year timescale, they were under the pressure of time, learning what to do and how to act unassisted. As such, in-situ guidance emerged as a resource to assist young adults on the go in the process of managing the illness more independently over the course of time.

3.1.2. Recovery Tracking

The participants stressed how cognitive impairments were a central feature of their illness. In particular, they emphasised how severe impairment of memory and attention made it hard to recall their own progress, which vastly impacted the hope of recovery. Since experiences were no longer stored in the memory, the good days often faded or even disappeared:

"*I often forget, how I was yesterday. It's difficult to remember, what I have been doing, and whether it was a good day or a bad day. It feels as if the good days calmly passes day by day*."

The pass of the good days was evident among the participants even though they stressed how the OPUS program had bettered their mental state significantly. Particular on "the bad days", the loss of memory impacted the hope of recovery, as it was difficult to believe that things would actually change for the better:

"*Will this ever be better? On the bad days, I really doubt it.*"

Thus, impaired memory left the participants in doubt of recovery, and maintained a strong presence of the bad days in the memory.

Several of the participants explained how their HCPs had encouraged them to monitor their health in an attempt to call to mind their own progress. Some had taken the word of advice using a diary to record the day; others had discovered that using the camera in their smartphone was a useful strategy to keep a sense of perspective, therefore keeping track of their progress over time. Yet others did not monitor their progress and had discovered how the "bad days" had the strongest presence in their memory.

A participant proposed that systematic tracking of the mental state could help to recall and tell apart the good days and bad days respectively, and emphasised how a display would be an important resource for believing in progress:

"*I think that getting things in black and white could help to convince me that I am getting better.*"

As such, it appeared that recovery tracking could help provide a more accurate and realistic picture of the process of recovery, particularly if the tracking were presented visually. Thus, recovery tracking emerged as an important feature to keep up the hope of recovery and to escape the mental captivity of illness.

3.1.3. Notifications of Illness Exacerbation

Fear of illness exacerbation was widely recognized by the participants. They emphasised how the OPUS program had improved their mental state significantly, yet, still they persistently wondered whether and when the illness would "strike" again. They were highly alert of early warning signs of impending psychotic relapse, as were their relatives. In fact, their mind was almost programmed to think that even small changes in the mental state could be deterioration:

"*What is this… a relapse? Honestly, that is always the first thing I think of. The thought of relapse and hospitalization really freaks me out.*"

The thoughts of relapse and hospitalization were dominant, and it appeared that the participants had difficulty "reading" the illness. Since they did not know what to pay attention to and what to let pass unattended, they identified all information from the senses as potential signs of impending psychotic relapse:

"*Is it the illness speaking now, or is it just me being young?*"

As such, lack of knowledge and insight into their relapse signature and drill left them in an incessant potential danger, not knowing for certain whether to be worried or not. The uncertainty was evident over the course of time. A participant explained how, still after one year in the OPUS program, he found it difficult to interpret fatigue, for example. This could be interpreted as a negative symptom (something normal for people suffering from schizophrenia), an early sign of illness exacerbation (a potential danger that should be acted upon) but also, a healthy reaction to living an irregular and "normal" youth life, occasionally having too little sleep.

The sustained problem of reading the illness prevented the participants from knowing whether to be worried or not, thus preventing them from "*becoming the captain of one's own life*" as one of the participants framed it. This restricted their ability to be proactive. Further, this left them watchful 24/7-worried and controlled by their illness, rather than certain and in control of it:

"*Sometimes it feels as if I'm at work nonstop. It would be so helpful, if I could get some kind of warning telling me when to be alert. Then I could focus less on my illness and more on just living my life.*"

Thus, notifications of illness exacerbation appeared to be a resource of paramount importance to promote a sense of confidence and control in their life with their illness, but also in "taking time off" from the illness, and focusing on being young rather than being ill.

3.1.4. Wired List of Medications

The participants stressed how the severe impairment of memory and attention, did not only impact their hope of recovery, but also their ability to keep track of their medications. Most stressed how they had control of taking their daily medication through different routines, but found it difficult to remember the names, types and doses of different psychotropic drugs, particularly ones used in the past. This left them powerless, particularly in stressful situations, where they had to account for it:

"*It's really difficult to remember all the different drugs I have tried the past year. If they ask me at the General practitioner or the Emergency room, I can't really report it, to be quite honest.*"

Having a sense of perspective of prescribed medication, both present and past, was greatly stressed as a means to be in control, and several stressed how a list of wired medications would be a helpful resource to recall this:

"*It would be a whole lot easier if I had some sort of list at hand that I could show them.*"

The emphasis of having a list at hand pointed towards the importance of ubiquity in order to support the memory. Thus, a wired list of medications emerged as an important resource to keep a sense of perspective and feel in control.

3.1.5. On-Demand Information

The need for widespread and timely information was evident among the participants. All turned to websites looking for information about the nature of illness, treatment options, rates of recovery, medication, as well as tips and tools to fight and manage the illness and their new life situation. This was particularly true when they had just been diagnosed:

"*At first, I really needed information. I searched the Internet for facts about the illness, just to know what I should expect the first couple of months… Because, F*** they were hard.*"

As such, the Internet was used as a tool to seek answers and self-educate. However, the information on the Internet, did not necessarily empower them:

"*It* [*information*] *can be really hard to understand, but also to relate to, since they use so many trade terms.*"

Thus, it appeared, that easily comprehensible information was key in order to keep a sense of perspective in the process of preparing for the time to come. As such, the participants pointed towards the importance of an on-demand information resource that was simple and enlightening, thus workable and applicable in the early phases of schizophrenia where the level of knowledge was low and the level of uncertainties high.

A participant shared the idea that the application could provide an encyclopaedia consisting of a knowledgebase with a search option similar to Google, and an interactive part where all the patients enrolled in the OPUS program could share their tips and tools, therefore providing each other with useful information through websites and articles. Thus, the active role in sharing and disseminating meaningful information was mentioned as an important aspect to take into account in the re-design of standard formats of information and learning aids.

3.1.6. Online Lifeline

The participants stressed the importance of easy access to their HCP. In this respect, they highlighted how their mobile phone was the platform commonly used to reach out for guidance and directions. This mode of contact was really reassuring:

"*I'm so happy that she* [*the HCP*] *has a mobile phone. She is always within reach. That is really comforting to know.*"

As such, the mobile phone served as an online lifeline ensuring that qualified advices was within reach regardless of time and place.

Reaching out for guidance and directions appeared to be equally important day and night. In fact, nights were often the time of day where the participants felt the biggest need for help and guidance:

"*After dark, I often feel anxious. That is the time of day where I feel most vulnerable.*"

The OPUS program, however, was only available during office hours. Consequently, it was not possible to communicate with the HCPs after 4 pm. Yet, several of the participants sent texts to the HCPs after hours, knowing that their messages would not be seen or answered until the next day. They had experienced how just getting things off their chest made them calm down and relax:

"*It's really nice that you can always write down things and send it off straight away, even in the middle of the night. Then* [*name of the HCP*] *can look at it when she has got the time: read through it, analyse it and send it back.*"

An important feature of the lifeline was customized guidance and directions. To this end, written communication was highly emphasised. The participants explained how their impaired memory and short attention span made it not only hard to focus, but also to remember the verbal advice received by phone. This made written guidance somewhat more supportive in controlling their new life situation:

"*It is really hard for me to communicate* [*verbally*], *since I have to think fast and remember what has been said afterwards. It is much easier and convenient to have things in writing.*"

As a result, it appeared that the mobile phone served the means of an online lifeline, making help and guidance feel accessible. Yet, the mobile phone emerged as a key feature in establishing a secure and empowering environment that enabled the participants to take time off from the illness, even in their most vulnerable hours where many questions and doubts arose.

Summing up, six ideas for supportive resources of power for the participant's to control their new life situation were identified. The findings are synthesised in Figure 3.

4. Discussion

The findings presented here provide new insights into the users' perspectives on the needs of support when being young and recently diagnosed with schizophrenia, including potential features that should be considered in designing a smartphone technology to accommodate these needs. Our study highlights that a smartphone technology should be designed to promote empowerment while responding to the needs required to confidently navigate this new life situation.

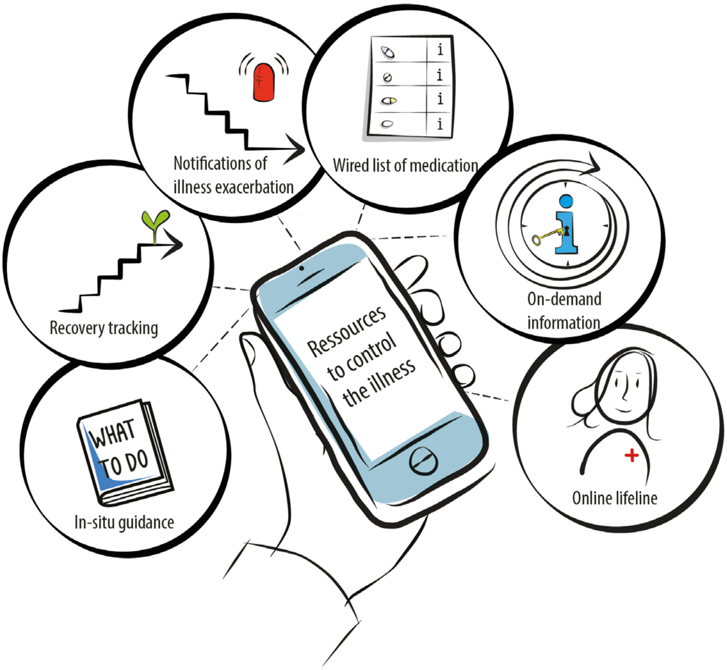

Figure 3. Synthesis of findings.

There is growing evidence that the perception of personal control plays a critical role in health and wellbeing [38], and finding ways to increase this power is important as a means to this end [39]. We identified six ways to increase this power in the early phases of schizophrenia, where the levels of knowledge are low and uncertainties high.

The analysis revealed that knowledge is a source of power, which is of great importance to control the new life situation independently. In-situ guidance, on-demand information and on-line lifeline were all different means to this end. The power of knowledge is highly recognized in psychoeducation literature [40], where evidence has been established that education helps individuals with schizophrenia gain basic knowledge on their illness [41]. Our study signifies that young adults with schizophrenia want to be educated in order to self-manage their illness, but they are unable to use the knowledge obtained outside the classroom to do this effectively. These findings are concurrent with previous studies claiming that knowledge gained through psychoeducation does not appear to help individuals with schizophrenia to manage their illness better or engage actively in the recovery process [41] [42]. Considered together, this substantiates the relevance of ubiquity to be able to assist young adults on the go, in the process of resuming the management of their lives independently.

The analysis revealed that memory is another important source of power to feel certain and in control of the new life situation. In this respect, recovery tracking and a wired list of medications came up as resources to help memorizing and keeping a sense of perspective. Cognitive impairments are a distinct dimension of schizophrenia and are highly evident in persons with this illness [43], as was widely evident in our sample. Cognitive deficits have emerged as an important new target in schizophrenia care, due to evidence suggesting that they are critically related to difficulties of functioning in everyday life [44]. Our study indicates that the smartphone may play an important role in compensating for cognitive deficits, therefore providing improved functioning in everyday life for those with schizophrenia. More importantly, our findings suggest that memory support may help keep the good days present, when the hope of recovery is hard to obtain. Thus, recovery tracking appears vital to sustain hope in the young adults on their journey towards mental health recovery.

Also, the analysis revealed how warnings are an important source of power to assert control. To this end, notifications of illness exacerbation came up as an idea to provide a sense of certainty and control in managing their new life situation. Birchwood proposes that persons with schizophrenia have a strong interest in learning to recognize and prevent impending psychotic relapse [45], and stresses the importance of promoting a sense of control through knowledge and insight into their relapse signature and drill [46]. This is in line with our findings, which eventually suggests that reading the illness and recognizing early signs of change is somewhat impossible in the early phases of schizophrenia, which makes notification of undesirable changes crucial to assert control. Notifications of illness exacerbations may be provided using smartphone technology.

The persuasive personal monitoring system, MONARCA, developed for the treatment of persons with bipolar disorder, is an example of this. This system uses an automatic trigger mechanism to detect early changes in the mental state through electronic self-assessments provided by the patients [47].

Summing up, our study advocates that control in the management of the early phases of schizophrenia may be achieved if support is extended into the everyday lives and homes of the young adults, where powerlessness, helplessness and worries develop. The smartphone, which enables digital engagement with patients in real time and real environments [48], may facilitate this process through easy and timely access to support. Firth and Torous [49] have documented high rates of engagement and satisfaction with apps in the care of people with schizophrenia. This further encourages the nascent potential of the mode of service delivery to accommodate the needs of young adults with schizophrenia at all times.

Study Limitations

The study was conducted with rigorous qualitative methodology, but there are some limitations.

The majority of the sample population were women. Since first episode schizophrenia incident rates are approximately two times higher in males than women [21] [50] our sample is gender biased. This might indicate that our findings are in favour of women, however, we did not see any distinct differences in relation to the needs of support in the two genders.

The sample was small and the study only included ethnic Danes from one outpatient clinic. Thereby, it reflects the culture, norms and values of young ethnic Danes, in a specific clinic at a specific time. It might be argued that a variation in ethnicity might have broadened the perspective of needs and ideas for their accommodation, particular since needs may vary over the course of an illness and depend on a patient's health status, demographics and culture [39]. This could affect the transferability of our results. Thus, it would be interesting to replicate the study in other contexts, countries and within different ethnic groups.

There were no distinct differences in experiences and statements from the participants; thus, the sample size appears to be adequate for the subject studied. However, the cognitive difficulties addressed in the findings, and widely documented in the literature [43], questions whether data saturation was actually reached. Even though the interviewer experienced saturation during each interview, there is a risk that some complexities did not unfold.

5. Conclusion

This study demonstrates that young adults with first episode schizophrenia need comprehensive support to become empowered to manage and feel certain in their new and changed life situation. Our study suggests that the smartphone may be used to foster empowerment by guiding the young adult's actions in situ, providing comprehensive and easily understood information on the go, allowing for recovery tracking, and notification of mental health changes, providing medication overview and giving easy access to HCPs. The high rates of engagement and satisfaction with apps in the care of people with schizophrenia encourage the nascent potential of the mode of smartphone service delivery to accommodate the needs of support at all times.

Clinical Implications

Our study advocates that smartphone technology holds the promise of empowering young adults newly diagnosed with schizophrenia to manage their new life situation confidently through easy and timely access to flexible collaboration and self-management resources. One thing to be aware of, however is, that patient empowerment may lead to over-involvement in own care [39]. Generally, over-involvement has gained less attention than under-involvement, although evidence has been provided that both types of mismatches affect patient satisfaction [51]. Since dissatisfaction is associated with disengagement from mental health services in young adults with schizophrenia [5], it appears crucial that HCPs continually assess with the patient whether the technology has become a burden. Otherwise, the technology may foster service disengagement rather than encourage and promote engagement. This strongly indicates the need for further research on the topic, and highlights that future studies could benefit from not exclusively addressing how the smartphone may promote empowerment, but also when and how such a technology may defeat its own purpose.

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PAPER II

Original Paper

A Smartphone App to Foster Power in the Everyday Management of Living With Schizophrenia: Qualitative Analysis of Young Adults' Perspectives

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Abstract

Background: Literature indicates that using smartphone technology is a feasible way of empowering young adults recently diagnosed with schizophrenia to manage everyday living with their illness. The perspective of young adults on this matter, however, is unexplored.

Objective: This study aimed at exploring how young adults recently diagnosed with schizophrenia used and perceived a smartphone app (MindFrame) as a tool to foster power in the everyday management of living with their illness.

Methods: Using participatory design thinking and methods, MindFrame was iteratively developed. MindFrame consists of a smartphone app that allows young adults to access resources to aid their self-management. The app is affiliated with a website to support collaboration with their health care providers (HCPs). From January to December 2016, community-dwelling young adults with a recent diagnosis of schizophrenia were invited to use MindFrame as part of their care. They customized the resources while assessing their health on a daily basis. Then, they were invited to evaluate the use and provide their perspective on the app. The evaluation was qualitative, and data were generated from in-depth interviews. Data were analyzed using a hermeneutical approach.

Results: A total of 98 individuals were eligible for the study (mean age 24.8, range 18-36). Of these, 27 used MindFrame and 13 participated in the evaluation. The analysis showed that to the young adults, MindFrame served to foster power in their everyday management of living with schizophrenia. When MindFrame was used with the HCPs consistently for more than a month, it could provide them with the power to keep up their medication, to keep a step ahead of their illness, and to get appropriate help based on their needs. This empowered them to stay on track with their illness, thus in control of it. It was also reported that MindFrame could fuel the fear of restraint and illness exacerbation, thereby disempowering some from feeling certain and secure.

Conclusions: The findings demonstrate that young adults diagnosed with schizophrenia are amenable to use a smartphone app to monitor their health, manage their medication, and stay alert of the early signs of illness exacerbation. This may empower them to stay on track with their illness, thus in control of it. This indicates the potential of smartphone-based care being capable of aiding this specific population to more confidently manage their new life situation. The potentially disempowering aspect of MindFrame accentuates a need for further research to understand the best uptake and the limitations of smartphone-based schizophrenia care of young adults.

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KEYWORDS

mental health; mHealth; mobile app; participatory design; patient empowerment; patient involvement; patient participation; schizophrenia; smartphone; young adults

Introduction

Background

It is well established that self-management knowledge and skills are the cornerstones of preventing exacerbations and relapse of psychotic illness [1-4]. However, many young adults recently diagnosed with schizophrenia skip their clinical visits [5,6], leaving them with only little knowledge and skill power to manage everyday living with the illness efficiently. This causes a serious threat to their current and future health and quality of life [7,8]. This proves the need to find new and innovative approaches to build competencies to empower them to manage the illness in the context of their daily lives. An approach could be smartphone-based care. The pervasive nature of the smartphone and smartphone apps allows to monitor health and for customized information and self-management tools to be disseminated in real time and in real-life settings [1,9-14], where and when it is needed [15-16].

Smartphone Apps for Schizophrenia Care

Smartphone apps have been developed for schizophrenia care [17-25], yet only limited attention has been paid to mobile health (mHealth) apps to provide illness management support to individuals with schizophrenia outside the confines of the mental health clinic [26]. A review of smartphone apps for schizophrenia identified only 1 app providing this kind of support [27,28]. This app offered prescheduled and on-demand resources to facilitate symptom management, mood regulation, medication adherence, social functioning, and improved sleep. Evaluation of the app in 33 individuals with schizophrenia or schizoaffective disorder showed that the participants were willing and capable of using the app independently in their own environment [28].

Although sparse, the existing literature indicates that a smartphone app is a promising way to empower young adults recently diagnosed with schizophrenia to manage everyday living with their illness. The viewpoint of this matter from the perspective of those living with the illness as part of their daily lives, however, is unknown. As interests in smartphone apps in schizophrenia care grow [14,17,20,24,25,29], this seems increasingly important to explore.

Qualitative research is a systematic inquiry seeking to explore, and eventually understand, the experiences of a particular group of people [30,31]. A qualitative inquiry may provide insider perspectives to aid the understanding of the viability of apps to make those recently diagnosed with schizophrenia more capable and confident in managing their lives. Using a qualitative inquiry, the objective of this study was, therefore, to explore how young adults recently diagnosed with schizophrenia used and perceived a smartphone app (MindFrame) as a tool to foster power in the everyday management of living with their illness.

Methods

MindFrame

Using participatory design thinking [32-35] and methods [36-38], MindFrame was iteratively developed to run on the Monsenso mHealth platform powered by Monsenso ApS. The platform has been technically and clinically validated in various clinical evaluation studies and randomized clinical trials (RCTs) [39]. First, interviews were conducted with young adults recently diagnosed with schizophrenia to explore their perspective of needs to be supported in the everyday management of living with the illness and to generate ideas of using the smartphone to accommodate the needs [40]. Then, young adults recently diagnosed with schizophrenia, health care providers (HCPs), a researcher, and software designers collaboratively designed resources to accommodate the needs [41]. Figure 1 shows MindFrame, which consists of a smartphone app that allows young adults diagnosed with schizophrenia to access resources to aid their self-management. The app is affiliated with a website to support collaboration with their HCPs. A comprehensive description of the resources in MindFrame, including its aims, capabilities, and intended use, is provided in Table 1.

Figure 1. Screenshots of the MindFrame app and the affiliated website.

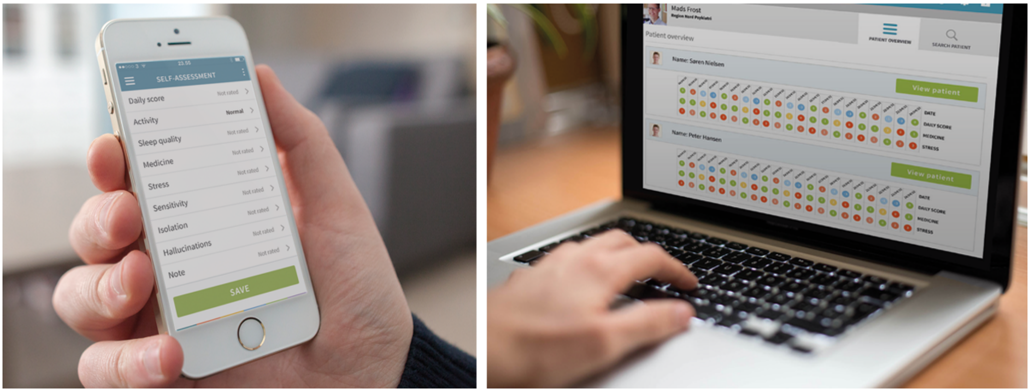

Table 1. MindFrame app resources.

Resource	Aim of resource	Capabilities of resource	Intended use of resource
Self-assessment	Monitor health	Data input to report the mental health state, for example, mood, activity, sleep, stress, medication, alcohol, hallucinations, hash, isolation, exercise, hygiene, paranoia, self-harm, sensitivity, and drugs. A note function allows explaining the assessment scores.	• The young adult and the health care provider (HCP) customize the assessment list together. • The young adult enters data every day using the app. A reminder is provided given the mental health state has not been reported at 8 pm. • Data are stored by the smartphone and transmitted automatically to a study server when internet connectivity is available. At this point, data are visible to the HCPs through the affiliated website.
Visualization	Psychoeducation	Data display of the reported mental health state.	• The young adult uses the displayed data to explore relations between symptoms, wellness, and behaviors alone or with the HCP. The HCP has an iPad with wireless internet connection and an external keyboard to access data on home visits.
Early warnings signs	Awareness on changes in health	Display of early signs of exacerbation of illness and suggestions of how to tackle changes to stay well.	• The young adult and the HCP identify the relapse signature and drill together and create customized feedback to stay alert to early signs of change in the mental health state.
Triggers and alerts	Notifications of changes in health	Data survey to notify signs of exacerbation of illness and to provide feedback on actions to take to stay well.	• The young adult and the HCP set up threshold values together to survey the self-assessment scores, for example, stress level higher than 2 (pretty stressed) on more than 2 consecutive days. When the threshold values are triggered, feedback on actions to take is provided.
Action plan	Strategies to stay in good health	Display of 3 levels of relapse prevention strategies: (1) stay well, (2) what can help, and (3) get help.	• The young adult and the HCP customize the action plan together.
Medication overview	Medication management	Reminders and tracking of medication adherence.	• The young adult and the HCP produce and update the medication overview together. • The young adult reports adherence to medication and changes in medication management. • The young adult is indirectly reminded about medication management as part of the self-assessment procedure.
Settings	Customization of resources	Customization of reminders and change of pin code. Access to user guide and a film introducing MindFrame.	• The young adult makes changes because of needs and preferences.

Research Design

The study design was qualitative and constituted the third phase of a participatory design process. The phases of the overall study are available elsewhere [40]. MindFrame was tested as an intervention during the period of January 1 to December 31, 2016. Subsequently, the intervention was evaluated.

Setting

The setting of the research was OPUS. OPUS is a bio, psycho, and social course of intensive outpatient care in Denmark available to young adults, aged 18 to 36 years, for the first 2 years following diagnosis [7]. The course of care is publicly funded. Effects of the OPUS program have been extensively researched and documented [42-44].

Intervention

MindFrame was implemented as an add-on tool to regular OPUS care in 1 OPUS clinic in Denmark. The criteria for participation in the intervention were the ability to read Danish and willingness to download and use the smartphone app.

The HCPs provided the young adults the invitations to use MindFrame. The invitation informed that (1) MindFrame had been developed in close collaboration with individuals with schizophrenia and HCPs from OPUS as a collaborative tool to support the everyday management of living with the illness, (2) they could use the app for free and for an unlimited period during the intervention period, (3) it was voluntary to use the app, (4) they could terminate use of the app at all times, (5) early termination of the app would not influence their course of care, and (6) they would be invited to share their views on the usefulness and impact of MindFrame at the end of the intervention period. Invitations to use MindFrame were provided throughout the intervention period. Thus, the length of the intervention and the time when the intervention was applied in the course of care differed from person to person.

When a young adult consented to use MindFrame, they were registered on the MindFrame website, and the smartphone app was downloaded from Google Play or App Store. An install guide was provided for this purpose. A secretary at OPUS made the registrations and handled any install problems. The registration procedure automatically generated an email that was sent to the young adult´s private inbox with a secure log-in code (see Ethics section). The log-in code was used to open the app. Individuals who did not own their own smartphone were offered one to use during the intervention period.

Training

The HCPs in OPUS were responsible for teaching and guiding the young adults in using and customizing the resources in MindFrame. Therefore, HCPs received training ahead of the intervention period. The first author and a MindFrame software designer conducted the training. The training was group-based and held as a 2-hour hands-on session, where the app and the website were carefully explained and then put into their hands to play around. The HCPs who were unable to partake in the group training were offered a one-on-one session by the first author. After the training session, the HCPs were provided a hard copy of a user guide describing each resource in MindFrame in depth, customization of the MindFrame resources, and how to receive first-level support. The first author was available for questions and supervision throughout the intervention period.

Evaluation

Following the intervention period, MindFrame was evaluated qualitatively. The evaluation process used for this study was inspired by interpretative hermeneutics. As such, it strove to bring out and manifest what is normally hidden in human experiences and human relations [45]. Data were collected through telephone interviews, which have shown to be productive in qualitative research [46].

All the young adults who had used MindFrame at some point during the intervention period were invited to participate in the evaluation. Thus, the recruitment strategy for the interviews was pragmatic and convenient [30]. The only criterion for participation in the evaluation was willingness to share experiences of MindFrame use by virtue of knowledge. The HCPs in OPUS distributed the invitation, and the first author phoned those consented to be contacted explaining more about the purpose of the evaluation and their rights as study participants. The young adults were encouraged to ask questions and were given time to make a decision on participation. All made their decision immediately and provided written consent. Characteristics of the evaluation sample are outlined in Table 2.

The interviews lasted between 35 and 66 min. They were conducted in Danish and recorded using the TapeACall app from Epic Enterprises. To guide and direct the interviews, a semistructured thematic interview guide [47] regarding personal power, knowledge power, and skills power [48] was used. To encourage the participants to speak freely about their views on how MindFrame contributed in the management of their lives with the illness, interview questions were open-ended. However, at the end of each interview, 15 close-ended questions were posed to work around the concept of empowerment and to prompt more direct answers. Examples of the close-ended questions are “When I use MindFrame I feel more in control” and “When I use MindFrame I become more uncertain of what is right and wrong.” Answering could by default be “yes,” “no,” or “I don´t know,” yet most answered in sentences. Given the questions had not been touched upon in the first part of the interview, the participants were invited to unfold their answers.

Analysis

An interpretative hermeneutical approach, grounded in the work of the German philosopher Hans-Georg Gadamer, guided the data analysis. A hermeneutic interpretative approach goes beyond mere descriptions to look for meaning embedded in common life practices. These meanings are not always apparent to the participants but can be gleaned from the narratives produced by them [45].

In Gadamer’s perspective, interpretation of meaning is not a stepwise approach. He emphasizes the canon principle that meaning comes from the hermeneutical circle of iteratively moving between part and the whole of the text [49]. Consequently, Gadamer does not provide a method for analyzing text, for example, interview transcripts, audio recordings, observations, and notes [50]. Nevertheless, he states that to obtain understanding, methodological direction through a systematic approach is needed [49].

To provide structure in the process of analysis, 4 tasks grounded in the hermeneutical circle served as a guide. The tasks that were derived from Gadamer’s work and proposed by Fleming et al [50] were as follows: (1) finding fundamental meaning of the text as a whole, (2) exploring parts for meaning, (3) comparing the meaning of the whole with the parts, (4) and identifying passages representative of the interpreted meaning.

Guided by hermeneutical thinking, the analysis began with listening to the tapes multiple times and obtaining a fundamental meaning of the interviews from an empowerment perspective. Then, the fundamental meaning was split into smaller parts that were explored by listening to smaller sections and individual sentences. Using the analytical question “what is said in relation to power,” sections and individual sentences were selected. To obtain meaning from the sections and sentences, they were deconstructed through interpretation, and the interpretations were constantly compared and contrasted with the meaning of the whole. According to Gadamer, there is no understanding without the activity of questioning [49]. Hence, explorative questions were constantly posed to the text in the process of interpretation. To ensure a rigorous analysis, questioning continued until an inner unity, which was free from logical contradictions, had been reached. At this point, categories of synthesized meaning were constructed.

Table 2. Characteristics of the evaluation sample.

Characteristics	Statistics
Gender, n (%)	
Male	4 (31)
Female	9 (69)
Age in years, mean (range)	24.8 (18-36)
Education in years , n (%)	
Low: ≤9	4 (31)
Middle: 10-12	6 (46)
High: ≥13	3 (23)
Employment status, n (%)	
Employed	7 (54)
Unemployed	6 (46)
Living conditions, n (%)	
Living alone	8 (61)
Living with spouse or partner	4 (31)
Living with family	1 (8)
Has children, n (%)	
No	10 (77)
Yes	3 (23)
Support worker, n (%)	
No	5 (39)
Yes	8 (61)
Weekly	4 (50)
Biweekly	4 (50)
Medication for mental health issues, n (%)	
No	4 (31)
Yes	9 (69)

Ethics

In accordance with the Danish law, a formal ethics approval of the study was not required. Authorization by the Danish Data Protection Agency (Datatilsynet) was obtained (2008-58-0028).

The study was consistent with the Declaration of Helsinki [51], meaning that the participants were fully informed about the purpose of the research. The informed consent was obtained verbally and in writing before the enrollment, and information about the right to withdraw from the study was provided. The participants were carefully explained that any withdrawal from the study would not influence their course of care.

MindFrame was established under the standard security approval and procedures of the information and technology department in the specific region in Denmark where it was applied.

Results

Use of MindFrame

As evidenced in Figure 2, a total of 98 individuals were eligible to use MindFrame during the intervention period and 27 used it. One of the individuals was excluded from using it as a result of not being able to speak Danish and 50 refused to use it. In 20 cases, individuals were not invited by their HCPs to use MindFrame. On being asked why, the HCPs owed the opt-out decision for exclusions to concerns that these individuals were too ill to use and engage with the app. Out of the 27 young adults who used the app, 13 participated in the evaluation.

The participants in the evaluation described MindFrame as easy and intuitive to use. In accordance with needs and preferences, the period of use of MindFrame differed among the participants. Some participants terminated use within 1 month (n=5), others terminated use within 2 to 3 months (n=4), and others used MindFrame for 6 to 12 months, terminating their use when the intervention period stopped (n=4). Reasons given for self-initiated termination of MindFrame included boredom, lack of motivation and energy, fatigue, and problems quantifying their mental health.

Perceived Use of MindFrame

On the basis of the participants' descriptions of use, 2 main and very different categories were generated about the usefulness and impact of MindFrame. When MindFrame was used with HCPs consistently for more than a month, it could provide the participants with the power to keep up their medication, to keep a step ahead of their illness, and to get appropriate help based on their needs. This empowered them to stay on track with the illness, thus in control of it. Furthermore, MindFrame could fuel the fear of restraint and illness exacerbation, thereby disempowering some from feeling certain and secure. This was observed when MindFrame was applied early in the course of care when the participants barely knew their HCP.

Five subcategories led to the 2 main categories. These are outlined in Table 3 and presented in the following section.

MindFrame Can Provide the Participants With the Power to Keep Up Their Medication

A total of 9 participants received psychotropic drugs for their mental illness during the study. They explained how their memory had been disabled by the illness, yet emphasized how MindFrame had helped them take the medication more regularly. As health tracking covered whether the medication had been taken, not taken, or taken with changes, the self-assessment procedure worked as a daily medication reminder, making it easier to comply with the medication regime. This was a comforting way of staying in control of the medication:

> *Every day I was reminded to take my medication through the app. That worked really, really well. When I was reminded about it I asked myself, "have you remembered to take your medication today." If not, I ran out to take it straight away.*

Some participants explained how they *forgot* to take the medication deliberately although they knew by heart that they needed it to stay well. One participant who had used MindFrame for 9 months explained how the self-assessment scores had helped her discover that irregular consumption of medication impacted her mental health state. Insight into this pattern of behavior helped her to make the decision to resume her medication regime:

> *Sometimes the scores made me realize that I needed to take my medication. It is easier to make decisions on [...] resuming taking the pills when I can see that my symptoms are progressing when I don´t take them.*

Figure 2. Flowchart of participants in the study.

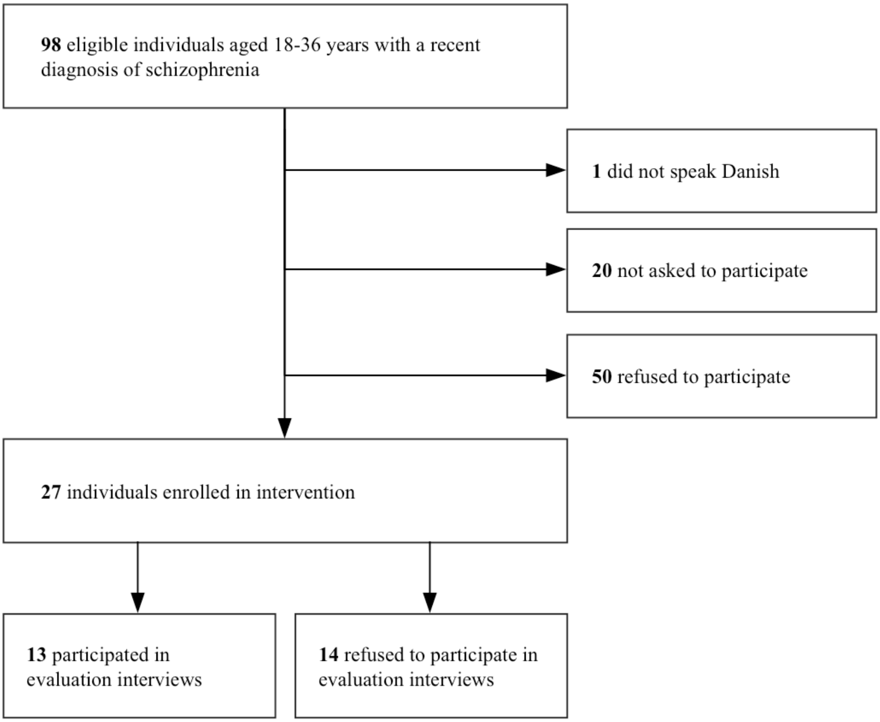

Table 3. The hermeneutical-inspired process of analysis governing the findings.

Words on tapes (quotations)	Immediate answers: what is said in relation to power?	Decontextualization through interpretation: empowering aspects of MindFrame	Categories	Result and major categories
When I first started in OPUS I had problems with compliance. MindFrame helped me to remember to take my pills.	*Helped me to remember to take my pills.*	Power to maintain medication	MindFrame can provide the participants with the power to keep up their medication	MindFrame can empower the participants to stay on track with the illness
Triggers and alerts made me conscious about signs I had to pay attention to, and act upon to stay well [...]. I believe that has helped me to stay on track.	*Made me conscious; pay attention; act [...] to stay well; stay on track.*	Power to act timely to stay on the track of health	MindFrame can provide the participants with the power to keep a step ahead of their illness	MindFrame can empower the participants to stay on track with the illness
MindFrame helped me to get anti-depressants pretty fast, when I needed it. I don´t believe that would have happened if my psychiatrist had not had the chance to look at my scores.	*Helped me [...] fast; when I needed it.*	Ability for health care providers (HCPs) to be more responsive to needs	MindFrame can assist the participants with the power to get appropriate help based on their needs	MindFrame can empower the participants to stay on track with the illness
If my scores were really bad, then, could they [HCPs] use my scores to put me under restraint? I was really uncertain of that in the beginning.	*Could they put me under restraint?; really uncertain.*	Lack of power to feel secure	MindFrame can increase participant fears and worries of restraint	MindFrame can also fuel the fear of restraint and illness exacerbation, thereby disempowering some participants from feeling certain and secure
Triggers and alerts gave attention to any early signs of change. What is this? Am I getting worse? That made me worried at some point.	*What is this?; Am I getting worse?; made me worried.*	Lack of power to feel certain	MindFrame can increase uncertainties in the participants about their mental health state	MindFrame can also fuel the fear of restraint and illness exacerbation, thereby disempowering some participants from feeling certain and secure

Thus, MindFrame seemed to provide the participants receiving psychotropic drugs the power to keep up with their medication so as to stay well. This was the case when the self-assessment procedure was used passively as a reminder to take medication or when the self-assessment scores were used actively to make the decision that medication should be resumed to stay on track.

MindFrame Can Provide the Participants With the Power to Keep a Step Ahead of Their Illness

The participants stressed how they had to react quickly to early signs of exacerbation of illness to prevent symptoms from progressing into full psychosis. The participants who had set up threshold values for triggers emphasized how MindFrame was a powerful resource to this end. They explained how their scores had prompted a trigger, which alerted them to be aware of the early signs of change, causing them to act upon these signs to stay in good health:

> *The trigger and alert function was really smart. It showed when things changed, and made one aware to do something in order to stay well.*

Awareness was brought to mind automatically through the visualization feature in MindFrame even when threshold values had not been set. Most of the participants made self-assessments on a daily basis for a period of time during the intervention period and emphasized how the display of their scores helped them to see *when* they should behave differently to stay well. This encouraged the belief that the illness would remain within their control:

> *It is so comforting that I know that the system shows me if the illness is getting worse. Then I know when I should act to prevent it from getting out of control.*

To stay in control of the illness, it was not enough to know *when* action should be taken. Knowing *which* action should be taken and *how* to stay on track were equally important. A few of the participants had customized their action plan with their HCPs, and they explained how the plan of action had provided them with strategies to stay well, saying, "The action plan tells me what to do to stay well." Other few participants had used the action plan without customization, which some found useful.

Thus, MindFrame seemed to provide the participants with the power to keep a step ahead of their illness rather than at the rare end of it by making them aware of when to act and how. This was the case when self-assessments had been conducted for more than a month and especially the case when the self-assessments were used with triggers and a customized action plan.

MindFrame Can Assist the Participants With the Power to Get Appropriate Help Based on Their Needs

All the participants described how cognitive difficulties challenged them when trying to remember how their health had been over time. In this respect, they stressed how MindFrame had empowered their memory to keep track of their state and progress:

> *It [MindFrame] helps me a great deal when remembering how I was last week or a couple of weeks ago. I cannot find back to how things were, MindFrame has helped me to keep track of this: how it was.*

The ability to keep track of their mental health state and progress was strongly emphasized by the participants, as it provided a solid basis for discussing their health and needs of care with the HCPs. To this end, most underlined how mental health tracking assisted their HCPs to ask more direct questions about the fluctuations in their mental health and relations between the mental health state and their behaviors and actions:

> *It has been easier for [name of HCP] to ask questions since she could see my scores: "I can see that you have had a bad day what happened that day?" She knew how my week had been and could ask more direct questions.*

Ultimately, this contextualized dialogue enabled the HCPs to be more responsive to the needs of the participants, which empowered them to receive the help they needed when they needed it:

> *I was in a period where my thoughts were getting darker and darker and [name of HCP] said to me: "I can see from your scores that your mood and sleep is not good at the moment. I don't think your antidepressants help you enough." She was right. Then the dose was increased, and after some time I started to get better.*

As such, MindFrame seemed to provide the participants with the power to get appropriate help based on their needs. This was the case when they reported their mental health state and the scores were used by the HCPs as a basis for assessing and adjusting care to their needs.

Several of the participants emphasized how they wanted their HCPs to take even more advantage of using their scores in their course of care. They explained how looking at the scores with the HCPs and getting expert help to add meaning to the score enabled them to better understand the causations of fluctuations in the mental health state and allowed the effectiveness of behavior change to be evaluated. They believed that learning generated from their own data could equip them to more confidently and independently navigate the everyday management of the illness in the long run.

MindFrame Can Increase Participant Fears and Worries of Restraint

As evidenced in the previous section, it seems that MindFrame could provide the participants with the power to stay on track of their illness. However, it also seemed that MindFrame could increase fears and worries in some of the participants, thereby disempowering them from feeling certain and secure. This was observed in 3 participants who had just been enrolled in OPUS and had only known their HCP for a short period. Shared for these participants were concerns of using MindFrame even before beginning its use. They stressed how they were worried that their HCPs could survey their mental health state on a day-to-day basis or keep them under *surveillance* in the time between consultations. They feared that surveillance could lead to situations where they were unwillingly put under restraint and committed to hospital:

> *My biggest concern about starting using MindFrame was that my nurse would observe my condition every day. Then, would there be consequences? Could she use my scores to admit me to the hospital?*

The fear of surveillance seems to fade with use. Two of the 3 participants stressed how concerns and fears had become less dominant over time as they had become more familiar with MindFrame and certain about the fact that their HCPs were only interested in their scores to provide the best possible care:

> *At first I was a bit worried that [name of HCP] could see all my scores, but when I found out that she was only interested in my scores to help me my worries disappeared.*

In 1 of the 3 participants, fears and concerns of restraint remained. Consequently, this participant did not report his true state of mind on his bad days. Rather, he touched up the scores making his mental health seem better than it was. This participant stopped using MindFrame within 1 month. The rest of the sample did not address fears and worries of restraint in relation to their mental health state being observed by their HCPs. Rather, they talked about surveillance of their mental health as a way of careful watching, helping them to get timely and appropriate help based on their needs.

Thus, for some participants, MindFrame seemed to increase fears and worries of restraint, which prevented them from feeling confident and safe. Worries and fears seemed to fade with use of the app but remained with 1 participant who embellished his data to stay in control.

MindFrame Can Increase Uncertainties in the Participants About Their Mental Health State

MindFrame seemed to provide the participants with the power to keep a step ahead of their illness, thus staying on track. Being a step ahead of the illness, however, was not always perceived positively. Two participants who had conducted self-assessments continuously for several months addressed this. Both participants felt that the notifications felt comforting and allowed them to act timely; however, occasionally it was stressful to be alerted about *all* the changes in their mental health state, as it left them wondering if their condition was worsening:

> *Being notified of all the changes sometimes made me anxious. It made me wonder if the illness was maybe about to get out of control.*

The 2 participants explained that doubt and hesitation about their mental health state was something they dealt with on a daily basis, thus it was not something new. However, they stressed how the notifications in some ways increased their uncertainty. They experienced this when there were incongruences between their perception of their mental health state and the state communicated by MindFrame. When their personal interpretation of the information gained from their senses did not match the notifications from MindFrame, they were left in doubt of what to think and whether or not to act:

> *When the notifications tell me to take care and I feel fine, it makes me question myself even more. Is it ok now, or should I do something?*

Thus, for some participants, MindFrame seemed to increase uncertainties regarding their mental health state and thereby disempowered them from feeling self-confident and on track with their illness. It was only observed in 2 participants, and they stressed that their uncertainty often disappeared when the notifications were shared and discussed with their HCPs.

Discussion

Principal Findings

This study explored how young adults recently diagnosed with schizophrenia used and perceived the smartphone app MindFrame as a tool to foster power in the everyday management of living with their illness. Findings from the interviews showed that when MindFrame was used continuously for more than a month and with the HCPs, the participants were provided with the power to keep up their medication, to keep a step ahead of their illness, and to get appropriate help based on their needs. This empowered them to stay on track with the illness, thus in control of it.

The findings showed that prolonged and continuous self-assessments were main components responsible for the efficiency of MindFrame. When data were collected consistently over a period of time, a picture of the mental health state of the participant was generated, and this picture worked as a tool to inform decisions about medication and as a tool to alert timely actions to stay in good health. In addition, prolonged and continuous self-assessments worked as a tool to inform the HCPs about the mental health state of the participant, which enabled them to deliver timely care more responsive to their needs. The findings highlight that as a tool to foster power in the everyday management of living with schizophrenia, MindFrame is mostly viable in young adults with schizophrenia who are willing, able, and capable of assessing their health over the course of time. Tenacious use of smartphone apps in the care for persons with schizophrenia may be difficult to obtain [52-55], which was also evident in our study where 5 out of 13 participants terminated use of MindFrame within the first month. This was true, although the resources in MindFrame were closely aligned with the needs and preferences of the intended user group, which is suggested to foster engagement [53,56-58]. This shows that MindFrame—despite being codesigned—was neither applicable nor appealing to all. The fact that only approximately 35% (27/77) of those invited to use the app accepted to use it further underlines this and indicates that MindFrame may not generalize to the broader population of young adults recently diagnosed with schizophrenia. Further research is needed to establish this.

The findings showed that collaborative use of MindFrame was another main component of its efficacy. When the self-assessment scores of the participants were shared with their HCPs, the HCPs were enabled to deliver care more responsive to their needs, which empowered them to stay on track. The participants stressed how they wanted their HCPs to take even more advantage of using their scores in their course of care. They believed that learning generated from their own data could equip them with the knowledge and skills to more confidently and independently navigate the everyday management of the illness in the long run. In line with previous research, the findings indicate that HCPs are responsive to integrating smartphone technology into young adult schizophrenia care [25], yet, that HCPs uptake could be better [59]. Successful implementation and dissemination of smartphone apps as part of schizophrenia care for young adult population will rely on provider uptake as well as client use [25]. Future research will need to address how to increase provider uptake and evaluate the impact of provider engagement on the ability to navigate the everyday management both in the short and long run.

As evidenced, the findings suggest that MindFrame can be used as a tool to foster power in the everyday management of living with schizophrenia. However, we identified 2 key aspects of use to take into account.

First, we identified that MindFrame could increase fears and worries of restraint, thereby disempowering some participants from feeling certain and secure. The fears and worries were related to data sharing when participants did not know their HCP very well. Ben-Zeev et al [14] investigated passive monitoring through sensors in a smartphone app. Using a sample of 11 inpatients and 9 outpatients with schizophrenia, for 1- or 2-week periods, respectively, they observed that approximately 20% of the sample felt upset by monitoring. This substantiates that worries related to health monitoring are rather common in individuals with schizophrenia even when data are generated automatically. We found that the feeling of uncertainty blurred when the participants got more familiar with the monitoring aspect of the app and their HCPs. This suggests that certainty may develop with use over time. However, we found that 1 participant embellished his data to stay in control, which accentuates that this might not always be the case. This advocates that health monitoring may have its limitations and highlights the paramount importance of carefully assessing the most appropriate time in the course of care to introduce and use an app for empowering purposes. Future research will need to look closer into the characteristics of those feeling upset from monitoring to fully understand its limitations.

Second, we identified that MindFrame could increase uncertainties about participants' own mental health state, thereby disempowering some from feeling certain and secure. The uncertainty was related to notifications of exacerbations of illness and arose when the app indicated worsening, but the participant was fine. The findings show that being notified may lead to an emotional response of disturbance when the notification does not correspond to the participant´s sense of health. The same was identified in individuals with severe and very severe chronic obstructive pulmonary disease. Hunicke et al found that disturbance arose when individuals felt better or worse than what the technology indicated [60]. The former is in line with our findings and highlights how monitoring may increase uncertainty even in individuals who have been living and managing their illness for a long time. The finding highlights the paramount importance of using an app as part of a collaborative partnership with the HCP to increase certainty. HCPs have clinical knowledge and insights of importance that would help young adults diagnosed with schizophrenia set up the right threshold values to notify changes in their mental health state and to adjust the values as the illness stabilizes or exacerbates. Given the young adult is left alone to do this, it is likely that the amount of false-negative or false-positive notifications may increase. Ben-Zeev et al stress that in the future, evidence-based mHealth apps will be downloaded directly onto the smartphone and used by individuals with little or no contact to mental health care facilities [28]. Our findings suggest that in the case of young adults recently diagnosed with schizophrenia, this may leave some worried and uncertain.

Schermer has sketched 2 possible future scenarios of the use of smartphone technologies in mental health care. One scenario is the *Big Brother scenario*, where monitoring technology will reproduce the old paternalistic paradigm of patient-HCP interaction in which compliance and monitoring are the aims. The other scenario is that it will create a new situation that centers on shared decision making and self-management, adding to the autonomy of the service user [61]. Our findings suggest for the latter scenario to be feasible.

Limitations

A number of key limitations must be acknowledged. The recruitment strategy restricted 20 individuals from choosing for themselves whether or not to engage in the intervention. Opt-out decisions where HCPs set up their own criteria for excluding individuals with mental health issues from participation in interventions appear rather common [62-64]. In our study, this may have contributed to an evaluation sample nonrepresentative of the population and the impression that MindFrame may not generalize to the broader population of young adults with a recent diagnosis of schizophrenia.

The evaluation sample was small, and most of the participants had positive attitudes toward MindFrame. The poor retention of study participants may have overvalued the positive effects of the technology. A replication of the study with a larger sample size and maximum variation sampling in the interviews could help clarify this. Contrary to convenience sampling, maximum variation sampling and extreme case sampling allow the researcher to purposefully select participants to learn from the most extreme and unusual cases [30].

The evaluation sample was one of convenience and consisted of 9 women and 4 men. Research has established that first episode schizophrenia incident rates are approximately 2 times higher in men than in women [65,66]. This suggests that our findings are gender biased and potentially in favor of women. A replicative study with a sample more representative of the population would be interesting to see whether these study findings are gender consistent. This might not be the case, as previous research has provided findings that male gender is a specific predictor of nonadherence to mHealth interventions [53].

The sample was interviewed post intervention. For the participants who had terminated using MindFrame after a short period, the evaluation was conducted several months after they had stopped using it. Given the cognitive deficits addressed in the analysis and broadly in the scientific literature [67,68], it is possible that our study design has contributed to recall bias, which may have prevented some complexities from unfolding. The research process, however, does not indicate this. When interview questions were posed, the participants easily shared their views and experiences.

Conclusions

Our findings demonstrate that young adults recently diagnosed with schizophrenia are amenable of using a smartphone app as part of their everyday life to monitor their health, to manage medication, and to stay alert of early signs of exacerbation of illness. Given the app is used consistently for more than a month and in close collaboration with HCPs, it may empower them to keep the illness within their control.

The findings encourage the application of smartphone-based care to aid this population to better help themselves in the time following the diagnosis. The disempowering aspect of MindFrame accentuates that a smartphone app should be used in a reflected manner at the right time in the course of care and with the right amount of support. Further research is required to understand the best uptake and limitations of smartphone-based young adult schizophrenia care.

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Conflicts of Interest

None declared.

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Abbreviations

HCPs: health care providers

mHealth: mobile health

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PAPER III

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ORIGINAL ARTICLE

A room for design: Through participatory design young adults with schizophrenia become strong collaborators

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ABSTRACT: *Smartphone technology is being increasingly viewed as key to engaging young adults with schizophrenia in their own mental health care.*

In an attempt to use smartphones as an engagement tool, we conducted a participatory design process, where young adults with schizophrenia (n = 4), healthcare providers (n = 7), software designers (n = 3), graphic designer (n = 1), graphic recorder (n = 1), and team leader (n = 1) co-designed a smartphone application for use in early phase schizophrenia care.

This paper reports the co-design process. Based on a variety of written data-sources, the paper describes if, and how, participatory design can help construct a physical and relational environment that enables young adults with schizophrenia to become active participants in the design of a more participatory mental health practice.

Guided by Etienne Wenger's construct of Community of Practice, three major categories of characteristics and construction of a physical and relational environment supporting and inspiring participation and engagement were identified: (i) a pre-narrative about a community of practice, (ii) the room for design is a community of practice and (iii) the community of practice as a practice of special qualities. It is concluded that participatory design can support and inspire participation and engagement in the development of mental health care with young adults with schizophrenia, given that the environment in which participatory design unfolds is transparent, flexible, secure and informal.

KEY WORDS: *cell phone, community of practice, participatory design, patient participation, schizophrenia.*

INTRODUCTION

Since the early 1990s mental health nurses have emphasized the importance of encouraging and promoting engagement of patients in their own care, and more recently engagement has been stressed as key to recovery (Barker & Buchanan-Barker 2002; Davidson *et al*. 2005; Topor *et al*. 2011). The promotion of engagement, however, is a challenge that many mental health nurses face (Elder *et al*. 2005), particularly in first episode schizophrenia care where participation is hard to attain (Kreyenbuhl *et al*. 2009; Stowkowy *et al*. 2012). Given that nursing is the discipline that enjoys the closest sustained contact with psychiatric patients, nursing might be seen as having the greatest opportunity to help or harm those who are on their journey towards recovery (Barker 2001). This further proves the need to develop mental health nursing into a more participatory practice, which meets the actual needs of those with first episode schizophrenia.

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Based on earlier research in health science, it is argued that smartphones can change the face of healthcare by making it more participatory (Boulos *et al.* 2011). This includes mental health care for young people (Seko *et al.* 2014). Since smartphones have no geographic limits, they provide the opportunity to facilitate access to self-monitoring resources, time sensitive health information, prompts and reminders, and personalized illness management tools, in real time and in real world environments (Ben-Zeev *et al.* 2013; Luxton *et al.* 2011) allowing for healthcare to be 'in the pocket' (Klasnja & Pratt 2012).

It is argued that for successful implementation of mental health technologies to occur, user-involvement in the design is crucial (Marcu *et al.* 2011). Involving those with schizophrenia in technology design, however, is not common practice (Wadley *et al.* 2013). This is in line with the broader field of mental health development, where user-involvement still is uncommon (Ion *et al.* 2010).

Motivated to engage those with first episode schizophrenia in their own care, we conducted a co-design process. Co-design means to develop technologies – *with* and not *for* users (Sanders 2013; Spinuzzi 2005). It draws on a participatory mindset, where users are seen as active partners or co-creators (Liem & Sanders 2013). An advantage to this approach is that the co-designers will take pride in, and ownership of, the process leading to sustainable results (Sanders 2013).

Participatory design (PD) was used to establish the co-design process. PD is a rigorous research method and design approach (Spinuzzi 2005) which draws on principles from Participatory Action Research (Clemensen *et al.* 2007; Kensing 2003). It uses a variety of generative tools to establish participation (Brandt *et al.* 2013; Sanders & Stappers 2014). The approach to establish participation in design and development of technologies has been widely documented in non-psychiatric populations (Bjørnes *et al.* 2011; Clemensen *et al.* 2007; Lucero *et al.* 2012; Waller *et al.* 2006; Wherton *et al.* 2015) and with dementia patients (Hanson *et al.* 2007; Robinson *et al.* 2009; Span *et al.* 2013). The potential of PD to make young adults with schizophrenia become engaged in designing a more participatory mental health practice, is yet to be identified.

Several researchers using PD describe the importance of the environment in which the process unfolds (Hagen *et al.* 2012; Hussain *et al.* 2012; Sanders 2013). Bødker *et al.* (Bødker *et al.* 2004) describes a preparation phase in which designing the room is stressed while Kanstrup *et al.* (Kanstrup & Bertelsen 2011) suggests it is essential to create a room where imagination is encouraged. Therefore, to explore the potential of PD in the mental health care setting it seems important that we are especially aware of the physical and relational environment the young adults with schizophrenia are invited to participate in, and participated in throughout the design and development phase. It was important that we constructed a fertile environment – "a room for design" – that enables the young adults with schizophrenia to become active participants in the design process. Using the frame "room for design" when analyzing the data, we explored how the room was constructed, maintained, and which elements were accommodated. Exploring both the intended and unintended elements that construct the room for design, it is possible to be aware of these in future studies using PD in the mental health care practice.

Therefore, the aim of this paper is to describe if, and how, PD thinking and tools can help construct a room for design – a fertile environment (Muller 2003) that enables participation and engagement in the development of participatory mental health care for young adults with schizophrenia.

METHODS AND MATERIALS

Research design and setting

A three phased PD process: (1) identification of needs, (2) design and development, and (3) pilot-test, was conducted from October 2012–August 2014. The process involved a total of 14 participants divided into two groups: seven young adults (age 19–31 years) diagnosed with schizophrenia (hereafter young adult users) and seven healthcare professionals (HCPs). All were related to one university hospital in Denmark.

This paper draws on data generated in phase 2 (design and development), where visions were formulated and sketched throughout 10 workshops. Four young adult users and seven HCPs participated at this stage of design. Five workshops were conducted with young adult users only (1,4,7,9,10), three with HCPs only (2,5,8) and two with both young adult users and HCPs (3,6). Each workshop including young adult users lasted between 3–7 h.

Recruitment and selection

Participants were recruited from a specialized outpatient clinic (OPUS). OPUS is an intensive and evidence based psychosocial treatment intervention for young adults (Melau *et al.* 2011) age 18–34 years diagnosed with first episode schizophrenia. Almost all individuals enrolled in the OPUS intervention suffer from severe symptomatology and require close contact with HCPs.

All seven HCPs working in OPUS were invited and accepted participation. Recruitment of young adult users was conducted in close collaboration with OPUS staff, using a purposive sampling strategy (Polit & Beck 2012). The inclusion criteria for phase 2 were comparable with those established for phase 1. Criteria for inclusion were simply willingness to share information by virtue of knowledge or experience. Exclusion criteria included the inability to provide written consent and problems talking or understanding Danish. Six young adult users were identified and participated in phase 1. Three out of these six continued as participants in phase 2. Two did not consent to proceed into phase 2, and the first author excluded one. All exclusions were due to social issues such as transportation and childcare. Given that the number of young adult users attending workshops was small, the identified problem of promoting engagement posed a potential risk of no-shows and cancellation, which again posed a potential risk of not being able to obtain the dynamics in the iterative process of developing the app. In order to secure that the setup was not too vulnerable, we made the decision of enrolling a participant in phase 2 of the study. The participant was not enrolled in OPUS, but had proven to be a valuable source in an earlier mental health developmental project using creative workshops.

Previous research has argued that a Patient-Clinician-Designer framework can overcome challenges in designing technology for mental illness, and help design solutions appropriate for all user groups (Marcu *et al.* 2011). Given that professional designers represent perspectives that might influence the adoption, acceptance and sustained use of the technology, they participated until a final concept for the app had been agreed on. The same applied to the HCPs.

Participants in phase 2, including their roles, characteristics, and workshop attendance are outlined in Table 1.

Tools and techniques for establishing participation

An important challenge to success in PD projects is to find appropriate ways of involving and engaging people in activities (Sanders *et al.* 2010). We used co-design workshops (Buur & Matthews 2008; Muller 2003; Sanders 2002; Scariot *et al.* 2012) to establish participation. The approach to design is emphasized as a means to seed positive social

TABLE 1: *Participants including roles, characteristics and workshop attendance*

Participants and roles	Characteristics	Workshop attendance
Young adult users (*n* = 4) Generate insights and manifest design ideas	Female. 21 years old. 1 year since diagnosis. Living alone. Social benefits.	1,3,6,7,9,10
	Female. 25 years old. 1 year since diagnosis. Living alone. Social benefits.	1,3,4,6,7
	Female. 31 years old. 5 years since diagnosis. Living alone. Retirement pension.	1,2†,3,4,6,7,9,10
	Male. 22 years old. 1 year since diagnosis. Living alone. Social benefits.	1,3,4,6,7
Healthcare providers (*n* = 7) Generate insights and manifest design ideas	Leading psychologist	2,3,5
	Clinical psychologist	2,5
	Nurse	2,3,5,8
	Nurse	2,3,5
	Occupational therapist	2,5
	Occupational therapist	2,5
	Medical doctor	2,5
Software designers (*n* = 4) Co-facilitate dialog and activities and transfer of sketches into app prototype	Experienced in mHealth development	1,2,3
	Experienced in mHealth development	1,2,3
	Experienced in mHealth development	2
	Experienced in mHealth development with end-users	4,5,6,7
Graphic designer (*n* = 1) Co-facilitate dialog and activities, logo design and user-interface design	Experienced in designing 'look and feel' with end-users of technology	3
Graphic recorder (*n* = 1) Co-facilitate dialog and activities, visual recording and visual notes	Experienced in visual process facilitation	1,3
Team leader (*n* = 1) Plan, coordinate and facilitate activities and dialogue	Clinical background in mental health nursing and formal education in health science	1–10

†Visual recorder

connections between participants, to immerse participants and to build a shared understanding about an issue that can be used as a basis to collaboratively generate, explore and evaluate new ideas or alternatives (Hagen *et al*. 2012).

Design artefacts were used to support active participation. The artefacts used were: storyboard, card sorting, mock-ups and paper prototypes. A storyboard is a visual tool to examine the tacit, invisible aspects of human life (Sanders *et al*. 2010). We used a storyboard, designed as a cartoon book, early in phase 2 as a tool to generate an understanding of problems, needs and preferences. Card sorting (Hagen *et al*. 2012) is a simple hands-on technique where problems, formulated as statements, are arranged in a category-three. The tool was used later in the process to collaboratively position preferences for help, and for defining success and discussing content. The statements were derived from a scientific article (Birchwood 2000) on early warning signs of schizophrenia. Mock-ups are visual proposals of how a product will look (Hagen *et al*. 2012). Mock-ups were used to sketch envisioned ideas in groups and to stimulate discussions in the final part of the process. When developing the look, feel and content of the app, mock-ups were used to set out guidelines for design. For this purpose a design catalogue representing different styles of fonts, colours, symbols, signs etc. was used to stimulate discussions. Finally paper prototypes were used to get feedback on content as well as look and feel. Paper prototypes are low fidelity manifestations of ideas or concepts (Sanders & Stappers 2014), that give an idea of how the final product will work and look.

Workshop activities were facilitated and managed (Kanstrup & Bertelsen 2011) to stimulate dialogue and interaction. To accommodate the cognitive limitations often identified in persons with newly diagnosed schizophrenia (Johansen *et al*. 2011), facilitation was supported by graphics. Support of physical and cognitive limitations that might affect participation, has been identified as one of the keys to success of PD with young people (Hagen *et al*. 2012). We used graphic facilitation, which is a technique that uses words and images for creating a shared language. It is practiced in that way, that the graphic recorder copies information that people share in workshops onto large charts that everyone can see. This helps to frame workshops and to capture information and ideas as they evolve (Bailey 2011).

In order to give direction into the process of design, the metaphor of “becoming the captain of your own life” was used. A metaphor is a linguistic artefact to communicate the essence of human experiences, which according to (Barker 2000) is an important vehicle for persons with mental health problems to express and explore selfhood. The metaphor was derived from individual interviews (phase 1) where young adult users described that the app should help them become the captain of their own life. The metaphor was objectified into drawings (e.g. a captain in troubled water, a lifesaver) and used as a shared point of reference throughout the process of design.

The setting of the initial workshop was a culture and activity centre. Previous research from the broader field of applying PD in healthcare innovation was used to choose the workshop setting. This research emphasizes the importance of choosing physical surroundings for innovation that facilitate a relaxed and undisturbed environment (Hanson *et al*. 2007), stimulate creativity and interaction (Clemensen *et al*. 2007) and encourages users to consider themselves as designers instead of patients (Glasemann & Kanstrup 2011). Over time workshops were conducted in a hospital setting (see analysis section).

Data sources and analysis

The paper is based on data systematically collected throughout phase 2 of the PD process. Data sources are outlined in Table 2.

Data were analyzed using a hermeneutical approach (Gadamer 2013). In the tradition of Gadamer it is rejected that hermeneutics is a step-by-step method, rather it is an explication of general principles (Kvale & Brinkmann 2009). Guided by canon principles of hermeneutical interpretation (Ibid), interpretation of meaning was constructed through a continuous back-and-forth process between parts

TABLE 2: *Data sources and content*

Data sources	Content
Hand-drawn workshop invitation (*n* = 1)	Personal invitation for workshop attendance
Workshop preparation descriptions (*n* = 10)	Agenda, tools/techniques, roles
SMS posted to young adult users (*n* = 680)	Communication prior to and between workshops
Email posted to young adult users (*n* = 69)	Communication prior to and between workshops
Workshop notes (*n* = 10)	Participants, actions, location, room reactions
Written reflection from young adult user (*n* = 1)	Experiences from the first workshop
Group interview with 4 young adult users (*n* = 1)	Experiences from the process of co-design

and the whole of the text (all data sources are seen as one text), which follows from the hermeneutical circle. We started with a vague and intuitive understanding of the text as a whole to identify salient characteristics, elements and actions of the room for design. The different parts of the text were then deconstructed using two analytical questions (AQ1 and AQ2). The questions, which were broad to open up the data, were: what is said regarding the room? And what actions are related to construction of the room? The different parts of the text were interpreted and out of these interpretations the parts of how the room for design was constructed and maintained were related to the totality, until an inner unity of the text free of logical contradictions were reached. For re-contextualizing the text as a whole the theoretical construct of 'Community of Practice' (CoP) (Wenger 1998) was used. This was reasoned in the early decontextualizing process, where data pointed toward the room for design as a room with the threefold characteristics of a COP (Wenger *et al.* 2002), namely: a shared domain of interest, a community that pursues the shared interest, and a practice.

Ethical approval and considerations

In compliance with the Helsinki Declaration (WMA 2013), the participants received oral and written information about the study and were included after providing their informed consent. The first author asked participants if they would like to participate in workshops, and they were given time to think about it. They were told that participation was voluntary and that they could leave the study at any time. Consent was confirmed orally prior to each workshop in line with good ethical practice in qualitative research with vulnerable populations (Seymour & Ingleton 1994).

The study obtained approval from the management department at Aalborg University Hospital – Psychiatry. The study was submitted to the local ethical review board. The board found that the study did not require ethical approval. The Danish Data Protection Agency registered and approved the study (2008–58-0028).

FINDINGS

The categories that emerged from the data analysis were as follows:

1 A pre-narrative about a CoP
2 The room for design is a CoP
3 The CoP as a practice of special qualities

The categories are presented below. Quotations governing the findings are presented in Tables 3–5.

A pre-narrative about a CoP

Based on the young adult users' descriptions in the early and late phase of the design process, about the introduction they were given ahead of the design process, a picture was generated that the room for design included a domain, a community, and a practice respectively. In other words, the young adult users experienced the essential elements of a CoP before their participation. Likely, this is important for the success of a design process as a notion of a CoP might inspire individuals to participate and foster engagement (Wenger 1998).

As outlined in Table 3 the experience of a CoP, prior to participation, arose from multiple aspects of the pre-narrative. The pre-narrative expressed a chance to contribute as part of a community of young adults, to a domain of app development, using a practice where individuals were seen as a knowledgeable resource instead of a patient in need of care. The first author communicated the pre-narrative. Text messages, emails and written material were used for communication. Appreciative inquiry was used verbally communicated, anticipating young adult users as valued community members and individual sources of expertise. A sentence sourced from the invitation to the first workshop exemplifies this: "*I need exactly your help, to design the most cool app*". For underpinning young adult users as sources of expertise, graphical representations were used. For example, young adult users were described as "*treasures of knowledge*" and were graphically displayed as precious treasures in a chest.

The room for design is a CoP

The room for design materialized as a CoP, where young adult users experienced a sense of domain, community and practice, respectively. The essential elements expressed by young adult users contributing to the perception of a CoP are outlined below and visualized in Table 4.

A sense of domain

As Table 4 shows, the development work was the focal point of the room – in other words: it was the joint (and pre-defined) enterprise creating a common ground for the CoP. The young adult users expressed positive attitudes towards the development work, where they shared a responsibility through the power to make decisions. Also they expressed positivity towards the way in which personal attitudes were transformed through the development process into something shared, concrete and tangible, which helped them discover and realize their own capabilities, competences and skills. Thus the domain and shared area of responsibility worked as an engine for learning and the construction of an identity as somebody of worth and value for the design.

TABLE 3: *The construction and characteristics of the room for design*

Interview text	Immediate answers AQ2	De-contextualization through theoretical interpretation	Category	Immediate answers AQ1	De-contextualization through theoretical interpretation	Category	Result = Major category
	Actions related to construction of room?	How is the room constructed?		What is said regarding the room?	Characteristics of room?		
To get a chance to participate in the development work was in a way to get wind of my old life before illness	To get a chance to participate	get a chance	Pre-narrative	the development work	development work	Domain	There is a pre-narrative about a CoP
Exited to meet the other young adults	Exited to meet	Exited		to meet the other young adults	meet (...) young adults	Community	
From the very beginning it was stressed that we had some knowledge (...)	From the very beginning it was stressed	it was stressed		we could manage to attend	manage to attend	Practice	
and there was an expectation that we could manage to attend for more than the 45 minutes HCP´s think we can	there was an expectation that we could manage	an expectation					

A sense of community

The room for design was a room for co-working, and as co-designers the young adult users were collaborators, thus legitimate members of the CoP. The young adult users described this membership as an affinity to the CoP which came from being together, doing things together, and having the feeling of being treated like knowledgeable and normal adult persons – from what Wenger (Wenger 1998) would call mutual engagement. As outlined in Table 4, a strong sense of community and belonging was related to the way in which the CoP was composed. The CoP was made up of like-minded individuals and this gave the community a homogeneous character. Despite being different persons with different problems and aspirations, all young adult users had their illness in common, and this made the community one of acceptance, understanding and inclusiveness.

A sense of practice

Co-designing took place in workshops. As seen in Table 4, this context of social practice was experienced as an illness-free setting, with the qualities of a conference, where participants met to share and combine knowledge into new insights. As a part of this conference setting, the young adult users experienced catering and shared meals, thus being a part of an experience perceived as a 'healthy and normal' environment.

The CoP as a context (practice) of special qualities

The room for design was a practice of special qualities. The qualities that the room was perceived to offer are outlined in Table 5. Actions done to accommodate the room are described below.

Transparency

Transparency, in terms of knowing what they would be exposed to, was a structuring quality of the CoP. Transparency first and foremost arose from setting an explicit agenda for the social practice of the community. This was done through workshop introductions where the aim, content and timeframe were always made very clear, and design artefacts were extensively described. In the first three workshops, where everything was new, the visualized agenda were posted on the walls in big templates. Text messages and emails were used for making the social practice

TABLE 4: *The participant's experience of the room for design*

Interview text	Immediate answers AQ1 What is said regarding the room?	De-contextualization through theoretical interpretation Characteristics of room?	Categories	Result = Major category
Great to discover, shit, we could do it! To see our attitudes transforming into something concrete	We could do it our attitudes transforming into something concrete	A room for development work	A sense of domain	The room for design is a CoP
Now we [young adults] had all the power in the [voting] notes. We were given post-it notes with the right colour code	we had all the power in the notes	A room with a shared area of responsibility		
When working together we were really just treated like ordinary adults, even some with a huge knowledge	working together treated like ordinary adults (...) with a huge knowledge	A room for co-working A room of collaborators	A sense of community	
You don´t feel judged, because all are in the same boat. They understand and accept	You don´t feel judged, because all are in the same boat	Being with like-minded		
Being at workshops was a bit like being at a conference. There was catering, and we shared our meals. It made it feel less illness-like	workshops like (...) a conference catering Shared meals	Workshops and conference setting A room with an illness-free setting	A sense of practice	

TABLE 5: *The context' (practice) special qualities*

Interview text	Immediate answers AQ1 What is said regarding the room?	De-contextualization through theoretical interpretation Characteristics of the practice?	Categories	Result= Major category
We knew what we would be exposed to	We knew what we would be exposed to	A transparent practice	Transparency	The CoP arise in a practice of special qualities
It was customized to the daily condition (…) this has also given a sense of security	a sense of security	A secure practice	Security	
The flexibility given to leave [the room] (…) has been comforting	The flexibility given to leave	A flexible practice	Flexibility	
The informal tone has been quite liberating. It makes you dare	informal liberating makes you dare	An informal daring practice	Informality	

transparent throughout the process of design. A total of 680 text messages and 69 emails regarding the social practice were sent. Emails included synthesis of findings from workshops made as visual notes. Early in phase 2 it became clear that emails were not necessarily read nor replied to by young adult users, which made text-messaging the primary e-tool for communicating the social practice.

Flexibility

Flexibility was another structuring quality of the CoP. Flexibility regarding the possibility to leave workshops if needed. Flexibility was built into the social practice by an enabled, explicit and legal way out. The provision of a way out was communicated verbally through the 'law of the two feet'. This 'law' was a standing agenda item in all workshop introductions, where the 'law' was graphically visualized as small shuffling feet. The law allowed for the young adult users to decide when and for how long to have breaks in workshops without the need to explain. The flexibility was described, as a comforting way to be a part of the CoP. Interestingly, the young adult users did not frequently make use of the flexibility provided, indicating that knowing a way out was sufficient.

Security

Security was yet another quality of the CoP. This quality was an outcome of the approach to establish participation. Security came from customization of support in workshops, in regards to the "daily condition". Customization was not a standing agenda item, but the need for support to attend and participate in the social practice was an area of recurring attention. In the first workshop, all young adult users, except the one that previously had participated in workshops, needed help to get started with the storyboard. The professional designers provided one-on one help by posing reflexive questions. One young adult user, which turned out to have low writing and literacy skills, had help to put his story into words and symbols. Two felt insecure about presenting their work to the group. In these cases the professional designers and the team leader presented the content of the storyboards and the young adult users supplemented. Over time, help from professional designers and the team leader disappeared, and all young adult users stood up to present, thus voicing their point of view.

Informality

Informality was the fourth and final special quality described as part of the CoP. Informality grew out of a liberating tone of the social practice, which was supportive to 'daring', thus a mediator for participation and collaboration. An informal tone was supported through creating an unpretentious physical environment for co-design. This was done using music, flowers and coloured drawings for decoration and by providing meals, snacks and fruit to support a relaxed ambience. When a liberating tone had been established the physical surroundings as well as decorations became redundant. As a result of this, workshops 4–10 were conducted in a conference room in the hospital, which was both cheaper and easier to plan. Interestingly, the relaxed environment remained in the hospital setting.

DISCUSSION

This paper reports the co-design process of MindFrame – an mHealth tool for collaboration and self-management in young adults with schizophrenia. The paper elucidates that as an approach to establish co-design, PD is feasible and PD thinking and tools have the potential to promote the construction of a fertile physical and relational environment – a CoP – that enables young adults with schizophrenia to become actively engaged in the design of a more participatory mental health practice.

According to Wenger (Wenger 1998) CoPs are an integral part of our daily lives. They are so informal and so pervasive that they rarely come into explicit focus, and most often they don't have a name or issue membership cards. Our study, however, signifies the importance of giving a CoP a name and a 'body' from the initial phase of design and development in order to create ownership and pride (Sanders 2013). We identified that the impression of exclusiveness that arose from the communicated pre-narrative of the CoP, was important to make the young adult users feel lucky, important, and valuable, not as patients, but as 'experts of their experience' (Visser *et al*. 2005). The finding raises a substantial question: would the CoP have emerged without a conscious pre-narrative? A systematic literature review of how, and why, CoPs are established in the healthcare sector, highlights communication as a means not just to establish CoPs, but also to maintain them (Ranmuthugala *et al*. 2011). The review underlines communication as an important recruitment strategy, but also as a strategy to promote engagement in the early phase of the establishment of a CoP. Our study uncovered that communication benefitted from being appreciative, suggesting that communication should be built upon a participatory mindset (Liem & Sanders 2013), that uses graphical representations and metaphors to create the notion of a creative community worth investing time and energy in.

It is argued that CoPs are social learning systems where mutual engagement, in terms of doing things together, talking together and producing artefacts together, allows for people to learn about themselves and the world accordingly (Wenger 1998). When people engage with each other and with the world, they learn what they can do, and how the world responds to their actions (Wenger 2000). In this sense, the CoP is a social learning system that profoundly shapes a person's experience of who they are. Our study confirms the notion provided by Wenger of a CoP as a resource for learning. We identified active membership in the CoP as a vehicle for the young adults users to re-discover themselves as somebody who "can do it" and someone with "power". In this sense, the CoP served as the basis of an 'identity changer' from being a 'receiver' to being a 'giver' or from being a patient in need, to being a designer of need. The study illuminated that learning in a CoP does not 'just happen'. Rather learning is an assisted and managed practice that heavily depends on a fertile environment as well as generative tools and techniques for generating insights and co-constructing knowledge. This advocates that the environment in which PD unfolds should be thoughtfully and carefully planned, and that participatory tools and techniques should not be applied strictly and by the book (Brandt *et al.* 2013). Since there is no fixed recipe for the application of PD to aid participation, it is important to be aware of what is accomplished using particular tools and techniques, and finding out how these in combination can create a format and procedures that create engagement and ownership of the results (Sanders *et al.* 2010).

Our study highlights that mental health nursing advantageously can become more proactive and systematic about developing and integrating CoPs into their strategy of user-involvement in the design of a more participatory mental health practice. However, working with CoPs on a strategic level accentuates a need to further understand how CoPs can be supported. Bringing together a group of people and calling them a CoP, does not mean that they necessarily will function as one (Li *et al.* 2009). It takes time and effort to establish a CoP and to learn what specifically facilitates and impedes it. What might work as a facilitating factor in one group of people may be a hindrance to another group working towards a different goal or under different circumstances (Ranmuthugala *et al.* 2011). Models and methods for stewarding CoPs to reach their full potential have been developed (Wenger *et al.* 2002). Such models and methods might be important frames to further investigate aspects of PD in a mental health setting and to explore how PD methods and thinking advantageously can be managed and facilitated to foster CoPs, not just in young adults with schizophrenia, but in the mental health population more broadly.

STRENGTHS AND LIMITATIONS

No previous studies have, to our knowledge, provided documentation of PD as an approach to establish a physical and relational room for design that enables young adult users with schizophrenia to become engaged co-designers of participatory mental health care. As such, this is an important study that adds to the knowledgebase on how to support involvement of mental health users in the development of mental health service responsive to perceived needs and visions of care.

The study used a hermeneutical approach to interpret meaning, and the interpretation of meaning ended when a "good Gestalt" – an inner unity of the text free of logical contradictions (Kvale & Brinkmann 2009) – had been reached. It might be argued that the number of participants included was small and that only one group was explored, thus the reliability of the study could be low. Therefore, it could be interesting to do a secondary study with a new group of patients to explore whether the elements of a community of practice once again was developed.

Our choice of including a young adult user participant in phase 2 with a longer duration of schizophrenia and previous experience from attending a workshop based on PD principles and PD thinking raise the question whether the homogeneity of the group might have been compromised? Our analysis does not indicate this. Rather our analysis points towards the advantage of including an experienced participant, as this participant might facilitate the construction and maintenance of a secure and informal environment that supports mutual engagement. This aspect could be interesting to explore further, to support the success of constructing fertile environments in future organizational user-involvement.

CONCLUSION

This study demonstrates that PD is a feasible and acceptable approach to establish co-design of a more participatory mental health practice with young adults with schizophrenia. To conclude, PD thinking and tools can support and inspire participation and engagement in the development of mental health care *with* young adult users suffering from schizophrenia, given that the environment in which co-design unfolds is transparent, flexible, secure and informal. The study shows that PD, as a method and an approach to co-design, has the potential to make even people with severe mental illness active and strong collaborative partners in the co-creation of future mental health care.

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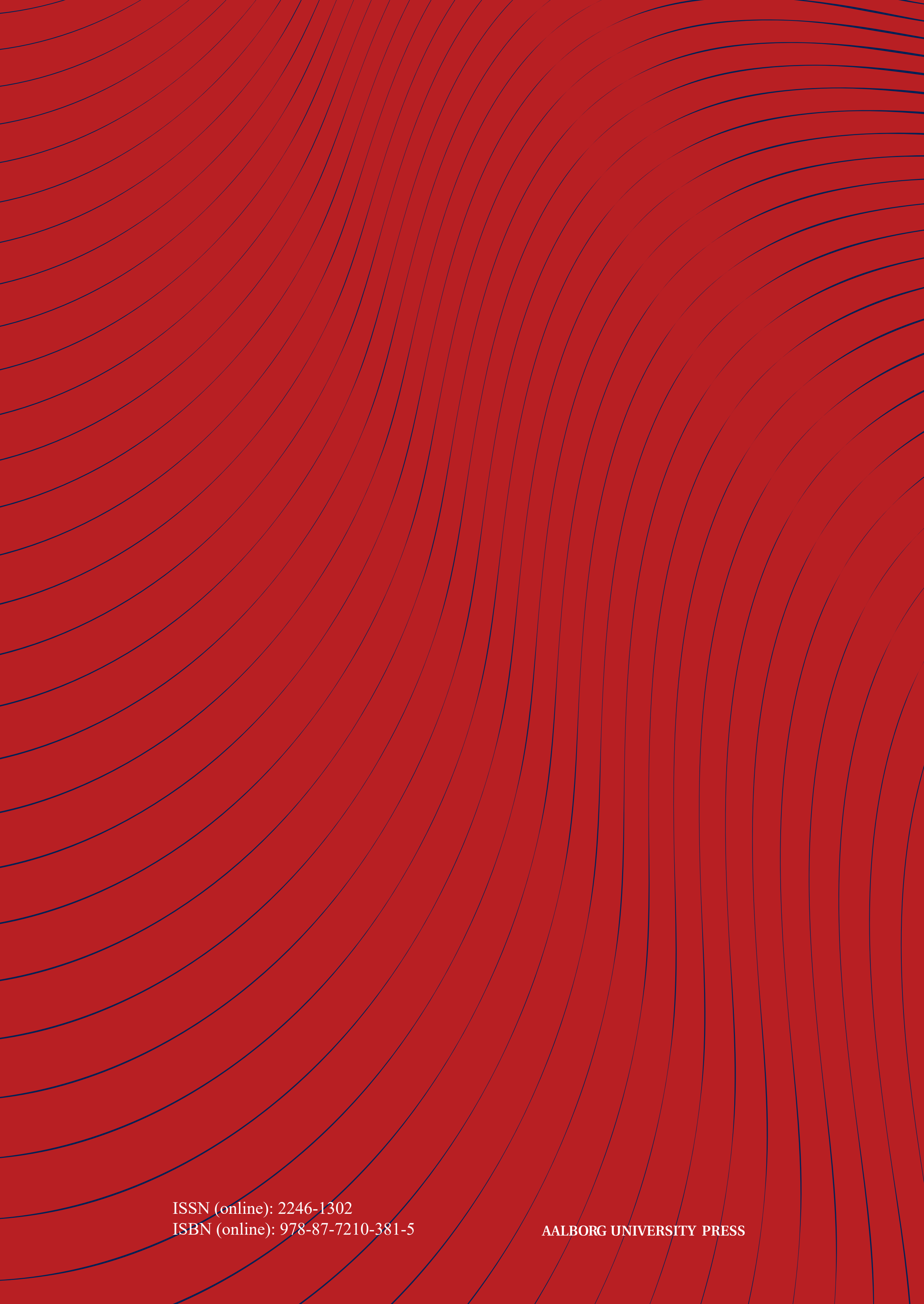

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