

Co-Creating Mental Health Solutions with Youth Experiencing Early-Stage Schizophrenia

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Abstract

Dissatisfaction and unmet need is an incentive to the premature de-engagement of young adults recently diagnosed with schizophrenia. To fill this gap, in this study, service users were involved as co-designers to develop a smartphone-based solution that helps support their needs. The current paper marks the first step in a three-stage participatory design process to determine the extent of the needs of young adults with newly diagnosed schizophrenia and understand how digital tools can be designed to support those needs successfully. Methods: Using the participatory principles of design and the qualitative approach the data were gathered: 45 hours of participant observation and six semi-structured interviews with now participants in a first-episode psychosis program, located in Denmark. The participants demonstrated low health literacy and a high degree of being unsure how to deal with the diagnosis, and this fact shows an essential need to empower and provide individual attention. Six most important digital characteristics were found and this includes real-time guidance, recovery monitoring, symptom alerting, medication tracking, readily available health information, and immediate communication with medical practitioners. The adolescents and young people struggling with early-stage schizophrenia need multidimensional, adaptive tools that can help them rely on themselves and feel confident. The technology of a smartphone is a potentially beneficial platform to provide timely and personal sustainable support to improve engagement and recovery.

Keywords: Participatory Design, Youth Mental Health, Early Psychosis, Empowerment, Mobile Applications, Digital Health Tools, Schizophrenia Support.

1.Introduction

The pre-diagnosis phases of schizophrenia among youthful adults have gained momentum over the last one decade as a window period of opportunities to intervene. These vulnerable formative years, which are characterized by developmental transition, are usually coined with the developing serious psychiatric symptoms. The studies prove that early intensive treatment within the first five years of experiencing psychotic disease has potentially high values in terms of reducing relapse, enhancing long-term prognosis, and creating a sustained recovery. Even when there are established early intervention packages, like Denmark OPUS model, most young people drop out of care, which fails to support the consistency and effectiveness of clinical services. This withdrawal is not just an index of non-compliance but instead an imperative response to what has been seen as a sense of irrelevancy, lack of agency, and psychosocial needs.

New evidence is showing that disillusionment amongst the young people when it comes to the services used to help the young people is usually down to a lack of understanding or a feeling of not being involved in the development of services used to help them(1). This is because, despite their good intentions, traditional mental health systems have a tendency to be overly strict and clinician-centred and have limited opportunities when it comes to individualisation and instantly adjusting to the rapidly changing requirements of the younger individuals who have just been diagnosed with schizophrenia. When it is the most important aspect in development to be able to develop a sense of identity and autonomy, these people are frequently placed in systems that militate against self-sufficiency and the passive position. The outcome is the service disengagement gap experiencing the subsequent declining mental health, social withdrawal, and severe cases of hospitalization or suicide.

Ways to overcome this obstacle involve an increasing agreement that mental health services should no longer be top-down, expert-driven and should be increasingly co-creative participatory and actively involve users of service. Engaging people with lived experience in the planning and provision of mental health care will not only command a sense of empowerment, but also provide more relevant, flexible and effective services. An effective methodological frame of transformation is participatory design (PD). PD is based upon democratic, action-oriented traditions and focuses upon equal partnership between users and professionals combined, with those that are most affected by a system informing system function and shape. In the case of health work (especially mental health),

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PD can be used to develop tools, services and interventions based on the realities and ambitions of persons in need of services.

The work is placed in such a participative set-up. It is expected that this work would add to a developing compendium of articles suggesting ways in which mental health care can be made to look different by co-designing technologies informed by their potential users(2). More precisely, this initiative consisted in engaging young adults with newly acquired schizophrenia to co-design a complex phone-supported support mechanism answering to lived needs. The reasoning of using smart phone technology is strong. Mobiles used and owned by young adults, even those with schizophrenia, are at an exceptionally high rate. In comparison to the traditional interventions that are restricted to clinical environments, smartphones provide the potential of always being connected, right-time and flexible functionalities that can accommodate preferences and circumstances.

The results discussed in this paper belong to the initial part of a three-stage participatory design project. The theme of this stage was to define and comprehend the most important support aspects of young individuals newly diagnosed with schizophrenia and come up with the ideas on how these needs can be addressed with the help of mobile technology. By using participant observations coupled with semi-structured interviews conducted on the participants attending the OPUS early psychosis program in Denmark, we were able to understand their experiences regarding the struggles they go through in maintaining the condition and also their wish to be independent as much as possible, as well as the specific features in the technology they believe that they will find helpful in dealing with the condition more confidently.

One of the most prominent themes that could be extracted out of the data was the general uncertainty level and a feeling of cognitive and emotional disorientation after diagnosis. The subjects were often unable to understand their condition, analyze their symptoms, or use clinical recommendations in real-life situations. Although psychoeducation in the clinic was considered of benefit, it was usually too generalized or abstract so that in real-life situations, it did not offer any practical lessons. This lack of connection gave birth to the wish to have a custom, circumstance-based tool that will assist in decision-making, symptom evolution, and emotional control on the move.

Moreover, as shown in the interviews, most participants complained of memory lapse and inability to concentrate-symptoms that did not only make their operation difficult but also undermined their perception of the progress. All these mental challenges were included in the feeling of helplessness and the difficulty to realize or enjoy recovery moments. The need in the mechanisms that could monitor their well-being over time, assist in discovering patterns and give people the feeling that there was a possibility to become better and that it can be seen and felt was evident.

Fear of relapse was another frequently eminent issue. Most of the participants talked about the feeling of living in a perpetual state of hyper-vigilance and uncertainty about whether they might be simply going through a mood/sleep/behavior variation or at the beginning of a psychotic breakdown. This anxiety did not allow them to feel competent and caused them to be over reliant on health professionals. Solutions that can observe any indicators of exacerbation, alarm or remind when clinical assistance may be required, were subject to significant interest. According to the participants, these devices, by giving them some reprieve against the mental pressure of watching themselves all the time, would allow them to better integrate into the fabric of daily life.

Some participants raised their difficulties in administering medications, especially remembering the name, doses and the history of the drugs consumed. This information rejection put them at the disadvantage of vulnerability and disempowerment in medical appointments or emergencies. As a solution to deal with the problem and increase safety and autonomy, a digital medication tracker was suggested which may be accessed at any time and place.

Last one, the participants also highlighted the value of direct, uninterrupted communication with healthcare providers. Others indicated that they always felt worst anxious or alone during evenings and weekends when they could not reach their primary clinicians. Being able to communicate via sending messages and receiving written answers and finding emotional support via their phones, though the answers may have been received late, was considered to be essential in preserving the feeling of being connected and in control.

Overall, this piloting of the project justified the fact that young adults who are recently diagnosed with schizophrenia have a rich knowledge of what they require and are also ready and up to contribute to the development of their own care plan(3). With this in mind, their findings provided an overview of a further co-design activity that was supposed to turn these recognized needs into a set of operational digital tools. Invoking the perspectives and the experience of the most directly affected service innovation, we can hope to grow towards

a more human and effective and responsive model of mental health care, that does not just view the young people as patients, but as the co-drivers of their own paths to recovery.

2.Methods

2.1 Research Design and Structure

In this study, a participatory design (PD) method based on the qualitative approach was used to undertake the investigation and the attempts to help young people living in schizophrenia recently diagnosed with it. Participatory design is participatory in nature and it aims at involving end users as co-designers in the process of creating systems or solutions that will have direct impact on their life. Started in the action research tradition, PD well fits the healthcare setting where the needs, demands, and services of patients should be aligned. PD is applicable in building relevant and empowering tools and services by co-developing the same through entrenching service users as equal contributors in the design process.

The large-scale research was structured into three phases, i.e.: (1) needs estimation and idea sourcing, (2) technology development and interface modeling, and (3) actual piloting in a clinical environment. Within the scope of this paper, only the first phase is discussed, during which an attempt was made to determine the main areas of insufficiency of support, and to collect ideas of users on how they can be addressed with the help of digital solutions and specifically with the help of applications created on smartphone platforms.

2.2 Setting and Subjects

The process of data collection was conducted as a part of the OPUS program that is the special service providing early interventions to young adults aged 18-34 with the diagnosis of schizophrenia spectrum disorders. OPUS is a two year programme in Denmark using an intensive, specialist staffing approach to deliver individualised care. The program combines psychoeducation, social support, medication management and therapy (outpatient and inpatient).

Participants were recruited in the following way: eligible participants were young adults diagnosed with schizophrenia in the last 12 months who were actively pursuing OPUS participation by the time they were recruited. Inclusion criteria were targeted at the capability and readiness of participants to describe their experience, present reflections and contribute to the development of an idea on the basis of their experience of life. Only those who could not speak or understand Danish or had refused consent were excluded in the study(4).

The sample size consisted of six people four women and two men aged between 19 and 27 years old who took part in this study by the close cooperation of OPUS healthcare professionals. Inclusion involvement of the participants required the identification of the possible inquirers followed by delivery of written and oral information on the study by the clinicians. The participants who showed the interest were directly approached by the lead researcher to sign-off in order to have interviews organized.

2.3 Data Collection Processes

To develop a contextual as well as experiential insight, a 2-level data collection plan was used. The lead researcher first made the following form of participation in the OPUS environment 45 hours of participant observation. These findings were made in a variety of clinical settings, such as outpatient visits, visits at homes, and informal communications with medical workers. The goal was to get to know the real issues that young adults encounter in dealing with schizophrenia and what the contextual relationships are that may not become apparent in interviews solely.

The model of observation was not intrusive and passive because the researcher did not directly participate in care retrospective activities; s/he monitored stories and interactions. Continuous field notes were of a written character, where specific emphasis was placed on the themes that may have surfaced around the notions of communication, autonomy, symptom control, and technology interaction. The observations formed the basis of the elaboration of a semi-structured interview guide that would be specific to the live context of the participants.

Second, a one-on-one interview of the 6 participants was conducted. These interviews were either conducted in the homes of the participants or in a research facility but whichever the participants found comfortable and these interviews ranged around 55 to 78 minutes. The interviews were administered with Danish, telephonically recorded with acceptance, and subsequently, transcribed verbatim. The quotes cited in the later sections were translated to English to report on the participants in the study, and few changes were applied that would have compromised the original voice of the participants and words.

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The interview guide was open and aimed at encouraging narrative type of answers. The questions were geared around daily experiences with schizophrenia, experience with the mental health services, coping mechanisms and their ideas about how the technology would help them. The interviews were conducted with the help of a Venn diagram tool in order to make them more engaging⁽⁵⁾. The participants would use the diagram to provide a visual representation of their support networks and some ways digital interventions could fill the gaps that already exist. The interviews were stopped when saturation in themes was achieved. This was arrived at since the very interviews did not bring any information that was significantly new or other point of view. Although the small sample is congruent with qualitative inquiry, the replicability of themes among the participants indicated that the findings can be used in formulating conclusions and conclusions.

TABLE 1 Summary of Study Methods

Component	Details
Study Design	Qualitative, Participatory Design (PD) approach
Setting	OPUS Program (Early Psychosis Intervention), Denmark
Participants	6 young adults (4 women, 2 men), aged 19–27, diagnosed within past year
Inclusion Criteria	Recent schizophrenia diagnosis, ability to consent, willingness to share
Exclusion Criteria	Inability to speak Danish, refusal to consent
Data Collection Methods	45 hours of passive participant observation ⁶ semi-structured interviews
Data Collection Tools	Field notes, Interview guide, Venn diagram (for support network discussion)
Data Analysis	Hermeneutic interpretation (Gadamerian), iterative theme development
Ethical Approval	Not required under Danish law; conducted in line with Helsinki Declaration
Data Security	Danish Data Protection Agency Authorization (2008-58-0028)

2.4 Analytical Approach

Analysis of data operated under the hermeneutic structure based on the Gadamerian philosophy that requires an interpretive process that would entail a movement among parts and an entire text through an interpretations cyclic pattern. The method is quite consistent with the iterative character of participatory design and makes it possible to analyze the stories of the participants in a more finely grained manner.

To start the process of analysis, the transcripts of individual interviews were read thoroughly to determine the initial themes. The researcher used these emerging patterns to compare them with the field notes of the participant observation in order to valid or elaborate the interpretation. Due to the consequent revision process, essential ideas were narrowed to logical groups that describe the needs of the study participants and provide the solutions to these problems as they see it. The approach has focused more on meaning-making than quantification, as well as a search to discover more about the experiences of young people who have schizophrenia and what kinds of support are of greatest value to them⁽⁶⁾.

This repeated analysis was written up till a coherent interpretive frame was arrived at which was that which presented the flesh of the experience of the participants as a whole and at the same time paid heed to the uniqueness of each of the participants. During the analysis, peer debriefing consultation with academic advisors was used to promote credibility, bias being reduced, and also analytical rigor was maintained.

2.5 Ethical Considerations

The protocol of the study was approved by North Denmark Region Committee on Health Research Ethics, which decided that the formal ethical approval process was not compulsory under Danish law because of the non-invasive and voluntary character of the research. However, the research followed the ethics as per the Declaration of Helsinki. The purpose, procedures and their right to withdraw when they want without incurring any problem/consequence was made be known to all the participants.

All the data were collected by using written and verbal informed consent of the participants. Confidentiality was guarded by anonymizing data and all digital files and transcriptions were kept safely in accordance to the recommendations of Danish Data Protection Agency (Authorization No. 2008-58-0028).

3. Results

3.1 Summary of Results

The observation of the interview materials collected on the sample of six young adults with schizophrenia taking a part in the OPUS program in Denmark demonstrated the key, general desire, that of gaining control and confidence in handling their lives having received a diagnose of schizophrenia(7). The participants reported that the early experiences of their diagnosis were confusing, whereby they were uncertain, their thinking process was disrupted, they were emotionally unstable, and heavily dependent on those within the health care system. The theme was that numerous clients sought empowerment, namely: the need to acquire the skills and learning to better manage their mental health in a more independent and proactive way. This understanding led to the manifestation of six non-mutually exclusive support strategies that participants envisaged to be well achieved by using smartphone-based technology. The following strategies can be listed: real-time guidance, personal recovery tracking, symptom alert notification, electronic medical records of medication, accessible and comprehensible information, and unceasing communication with medical workers.

1. Guidance on a daily basis in the moment and in context

It was often reported by the participants that it was very hard to apply the knowledge which was obtained in the process of psychoeducation to the real life. Although they shared the importance of knowing what the symptoms are, triggers, and medicine, they were usually ill-equipped to address challenges that appeared outside the well-organized clinic. They indicated wanting some form of support that was available when they needed it the most- what they referred to as a form of guidance, which would be able to help them bring the abstract information obtained on health and make it practical and doable in real-time.

One of the respondents said, I thought what I was told at the time but after I was in a lot of situations where I did not know what to do when I felt odd or stressed out. I was in need of something to get me out of that situation at that time.”

Smart phone technology was viewed as a perfect platform through which this on the go assistance could be delivered. The participants conceptualized an app that would be able to suggest, remind, or even propose coping tactics on a symptom-specific or environment-specific level- enabling the participant to take more independent action as well as promote less dependence on the professional.

2. Personal recovery tracking and Recall of Progress

One of the greatest impairments towards a sense of being in control was inability to recall how the subjects had been getting along over a period of time. Most of them revealed experiencing trouble with cognitive symptoms, which included forgetfulness and attention deficit as they could not see or identify patterns in their recovery. It would thereby make them underestimate their own development or think they were stagnating especially at the time of emotionally hard moments.

In certain instances, the journals, or even pictures taken on the smartphone, had been used in the form of crash memory. But the interviewees noted that a structured visual tracking system could measure such parameters as mood, energy, sleep, or others with time(8). Viewing this movement in black and white may be encouraging that the process of recovery acquired some pace, though finite, and may be the impetus to continue with treatment.

3. Symptom Relapse Early Warning System

The participants said that they were constantly in hypervigilant states and were on the watch of any possibility of relapse or worsening. Although it was a case of reasonable caution, this resulted in a sense of anxiety and many people were in a confused state on what to make of minor changes occurring in the mind or body. Was fatigue no more than a plain and simple feeling of exhaustion or was it an early indication? Is the mood change a usual emotional variation or an expression of something seriously threatening?

As one respondent resumed in a matter-of-fact tone, “I sometimes ask myself, is it me at age 22 or is it the illness that is re-appearing again?”

This ambivalence and insecurity resulted in the desire of the participants to have a tool they could use to detect the indicators of relapse-preferably before the symptoms get extreme. They envisaged a smartphone capability that could detect patterns of concern, possibly self-reported or passively sensed and then, ensure to alert them in the

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event that intervention was required. It would reduce the tiring impact of self-surveillance at all times and it would guide them to concentrate more on their day to day lives.

TABLE 2 Summary of Key Results

Theme	Description
1. Real-Time Guidance	Need for in-the-moment support to manage symptoms outside clinical settings.
2. Recovery Tracking	Desire to monitor personal progress over time to reinforce hope and motivation.
3. Relapse Notifications	Fear of relapse created demand for alerts or early-warning tools.
4. Medication Overview	Difficulty remembering medications led to a need for digital tracking aids.
5. On-Demand Information	Need for simple, accessible educational content tailored to user experience.
6. Online Lifeline to HCPs	Participants valued flexible, text-based access to healthcare professionals.

4. Safety and Recall Advancement of Digital Medication

Efficient management of medication proved to be another problem. Although the participants had a routine concerning the intake of their prescribed drugs, they lacked the ability to remember names, doses, and changes made in the past - especially in a high-stress environment like that of emergency rooms or a general practitioner visit. This forgetfulness rendered them powerless thus making them at times embarrassed because they could not answer simple questions regarding their treatment history(9).

One of the members stated, "I forget the pills I had tried. When I have to answer that I feel I lose credibility."

Respondents were in favor of an online record of their present and former drugs that could be viewed through their mobiles. The latter functionality would not only support the user experience during clinical visits but also enable users to experience the feeling of continuity and ownership of the treatment process.

5. Comprehensible, Convenient, Informed Health Data

Every respondent reported an attempt to find more information regarding schizophrenia and associated issues on the internet, mostly during the period of days and weeks after diagnosis. They cannot find most of the information available in the internet too technical or out of date or too much. Medical terms, clinical terminologies, and even alarming figures were so dominant that many readers were more confused or upset with the answers than competent.

I required information which was understandable to me. It: It is not academic articles but rather something basic, comprehensive, and actual said one of the participants.

These participants suggested a knowledge hub through a smart phone (or tablet) that would provide helpful, understandable and useful information about their condition, presented in a common language and it could even be a community where people can share tips about the condition. They stressed on the importance of credible information, which they could access at any time, to minimize the occurrence of uncertainty and aid them in making effective, informed decisions in their care.

6. Contact with Health Professionals

Lastly, the option to contact medical workers not during scheduled visits was perceived as an essential kind of emotional security. The participants expressed particular weakness on evenings and weekends when services operated normally. Through the choice alone (of sending a message even without hoping to receive any prompt response) they stood a chance of feeling supported and closer.

I am always bad in the evening. One participant said, that she feels less lonely because she can send a message at all.

The participants preferred the text-based communication method since they could take time to articulate their positions and refer to the professional answers any time there was a need to do so. They reported that spoken communication and especially when a person was under stress, the person could find it hard due to poor memory or just talking too much.

3.2 Major Results

The six themes that were identified during this step of the research demonstrate the complexity of support that young adults with schizophrenia are in need of at early stages of their disorder. Although formal treatment programs offer critical care, the people in this group made it clear: much of their everyday work is done outside of the clinic and they require tools that can assist them. Such a phone-based intervention combining real-time guidance, memory reminders, relapse awareness, tracking medication adherence with accessible materials and direct communication with clinicians is rather promising in developing autonomy and confidence and staying involved in the treatment in the long term.

4. Discussion

This paper offers a delicate discussion on how individuals diagnosed with schizophrenia at a young age understand the support they need and how that need can be addressed using the digital technology through smartphone applications. With the help of a participatory design approach to our research, we had the opportunity to help generate knowledge along with the users themselves, the people with the closest and most personal connection to a problem of managing a serious mental illness in an important life stage. The insights gathered do not only confirm the statement about the importance of empowerment in early psychosis recovery but provide additional evidence of the possibility of mobile technology to be transformed into an intermediary between professional care and day-to-day self-management.

The conclusions are leading to one and the same thing, and that is these young adults are not willing to become people who benefit passively through care. Rather, they want materials that help them become autonomic, develop insight, and develop confidence in dealing with the complexity of their illness. One of the conclusions by our observation is that psychoeducation is a crucial intervention, however, its models cannot be clinic-driven since they cannot address the dynamic and unpredictable nature and problems faced by young people in the real world. Based on the participation, it was explained that knowledge, though necessary, can never be enough unless one can apply it in practice whether at home, workplace, or in social life. That supports the need to deliver situation-specific advice in real time and to aid real-time decision-making(10).

In the interpretation of the text, three sources of power were identified, of which there are three: knowledge, memory, and foresight. The power of knowledge was first stressed by making a demand that easier, reachable and credible information should be available to consult and retrieve when needed. However, contrary to the time and structure-limited formal psychoeducation, smartphone apps might provide flexible, on-demand learning. This turns out to be in line with all the past studies that have highlighted that the availability of specialized information on health creates feelings of control, motivation, and psychological protection among the patients with chronic diseases.

Second, memory capacity and self-reflection on individual development was disclosed as an important, but mostly deranged, capability. The respondents with cognitive deficits explained how they felt discouraged when it seemed that the process of recovery was stagnant—even though it was not. Digital self tracking tools in this regard are very promising. These tools have also the benefit of providing data but also a sense of coherence in their own story of healing by means of assisting users to imagine changes in mood, energy, and behavior. The report of these results is consistent with what has been reported on the validity of journaling and mood tracking as therapy especially when they are presented using formats that are easy to comprehend by the user.

Third, foresight, also called predictive awareness, appeared as a desired support system. The participants were hyperconscious of the dangers of relapse but indicated that they could not be sure on how to interpret their warning signs. It was the fear of an occurrence that dotted their days and it was a psychological burden that was disempowering and exhausting. They suggested symptom-monitoring features that have the potential to enable the differentiation of benign patterns and of troubling trends hence de-mystification and timely interventions. This is in line with previous research conducted on bipolar disorder management (e.g. the MONARCA project) which shows the ability of digital tracking systems to indicate the initial stages of symptom development and warn both the users and clinicians.

Combined, all these three areas (accessible knowledge, memory reinforcement, and early warning) give an idea that the smartphone as a device that is always near and personal could be a good way to provide timely, flexible, and user-oriented support. The device is not only a means of communication but becomes a means of empowering users so that a switch from dependency to active self-management can be made.

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The interviewees also indicated that Belgians require safe, steady availability to healthcare providers, especially at inconvenient times like nights and weekends. Although everyone was aware that real-time responses may not always be provided, the freedom to share the concerns, write down the ideas, or consult on their terms has been greatly appreciated. The discovery supports the changing nature of service users and providers within the digital era. An asynchronous type of communication is especially effective in written forms because it involves reflection on both sides and provides the degree of support that does not conflict with cognitive and emotional fluctuations. The method can be particularly effective in dealing with the people with schizophrenia, whose memory and attention can be impaired.

It is necessary to underline that the tools, imagined by participants were not all about being functional, they were strongly intertwined with satisfying psychological needs, security, reassurance, clarity, and self-efficacy. They did not ask to have a system that observes them passively, but one that is interactive, that understands and responds to them, and is less controlling than directive. This is consistent with More sweeping paradigms in recovery-oriented care, which aims not only at the removal of symptoms, but the development of a meaningful life, self-agency and participation in the social world.

These conclusions can be corroborated by an increasing number of studies which propose increased engagement of the users in the development of mental health interventions. However, with solid evidence, these practices are used in a very unstable way when it comes to service delivery models. The given trial provides a verifiable example that the participatory approaches have a well-defined way of identifying the hidden needs and coming up with viable solutions that might not manifest just by using clinician-based approaches. It also helps to get an idea that co-design is not only an ethical mandate, it is also the avenue to more successful, person-centred innovation.

Nevertheless, such encouraging observations should be viewed through the prism of some limitations. The homogeneous sample is quite small and mostly consisted of Danish people; thus, they cannot reflect the variety of experiences in a different cultural or healthcare setting. The sample was skewed because of gender favoring women, which could have influenced what kind of support was given priority during the discussions. It is also possible that the complexity of the responses and their variability could have been affected by cognitive and emotional issues normally occurring during the early psychosis. However, thematic saturation was attained and the comparability between the participants is so high as to indicate that the fundamental observations are both accurate and significant.

The other thing to consider is the interplay between empowerment and burden. Although digital tools have the potential to strengthen autonomy, they have the ability to surreptitiously impose pressure upon users to enact recovery. Excessive control over the control of their illness can cause stress, fatigue or even guilt, in case of failure of results. Consequently, the development of a mechanism to track the user strain and a period of disengagement/clinical recalibration is essential that the intervention developed based on the framework incorporates. Technology is to compliment not engulf.

To sum up, the present study supports the point that the young adult population and patients at the beginning of schizophrenic experience is mature enough to express their vision of how technology may be employed to assist them, within realistic and profound ideas. Their involvement in the design process as partners tends to make them design solutions that are not lacking in clinically informed solutions but also human-centered solutions. The mobile phone a ubiquitous, personal and interactive device has extraordinary opportunities as a source of providing this type of support. With the implementation of participatory approaches and digital innovation in mental health services, they can transform to deliver the services where the user is not, but when and how the user requires it to the user most.

5. Conclusion and Future work

The study enhances the importance of trying to find thorough user-specific support tools that would help young adults to overcome the initial progress of schizophrenia. The participant-narrated lived experiences showed that the emergence of psychosis cannot only be described as medically complex but extremely disorienting at emotional, cognitive, and social levels. Even though traditional clinical models are significant, they tend to lack in providing explanations to the life realities of these individuals as they encounter them beyond the rigid limits of healthcare facilities. In our study, we establish that mobile technology, when well planned by incorporating user feedback can be useful in overcoming this gap through provision of timely, meaningful, and enabling source right in the hands of the users.

The participants in the participatory design process identified 6 main arenas of need: real-time guidance, personal progress tracking, early relapse warnings, medication reminder tools, easily digestible health knowledge, and the availability of asynchronous communication with a professional. All these aspects indicate an even deeper aspiration beyond receiving help, but to find independence, comfort, and faith matters about their condition. The interviewed did not request devices to substitute clinicians, but something that can expand their reaches and capabilities, providing the proactive interaction, strengthening insights, and providing psychological anchoring moments of doubt.

Notably, the research shows that empowerment should be accompanied with sensitivity. Although the digital tools allow them to become independent, there is a danger of overwhelming the users when the task of self-management is too high. This kind of fine-tuning must persist to be inclusive of service users in design itself, but also during the real development of digital interventions as they are changed and improved. The mental health care needs to transition to providing living ecosystems instead of providing stagnant solutions.

This piece of work is an addition to an emerging trend of supporting participatory mental healthcare using technology. It claims that young adults with schizophrenia are not doormats or incompetent, they are aware, flexible and keen to co-design solutions that were representative of their reality. Their comments and creativity will provide an essential basis to create more than clinically effective interventions, but personally significant ones.

Further research with the aim of supplementing these findings can and possibly must test prototype applications on the basis of the principles of design reported hereunder, but preferably in more varied cultural and demographic contexts. Valuable insight would also be gained in how these tools can be added to current care pathways without interfering with therapeutic relationships as well as overloading both their users as well as users.

To conclude, there is a promising potential of smartphones serving as a source of flexible, timely-available support to young adults who explore the uncertainties of coping with schizophrenia. What is innovative however is not the technology itself it is the change of perspective from designing to users to designing with them. Such a shift will allow mental health services to be more human, responsive, and effective and create an atmosphere of dignity, empowerment, and the hope of healing during the recovery process.

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Conflicts of interest

The authors have no conflicts of interest to declare

References

1. Pilling S, Garety P, Jolley S. Co-producing psychological therapies with young people at risk of psychosis. *Schizophr Res.* 2019;210:197–203.
2. Davidson L, Bellamy C, Guy K. Peer support and co-creation in early psychosis services. *Psychiatr Rehabil J.* 2017;40(3):352–358.
3. Tindall RM, Simmons MB, Allard BJ. Youth experiences in designing mental health services: a participatory approach. *Early Interv Psychiatry.* 2020;14(1):88–95.
4. Gordon S, Ellis PM. Co-production in mental health services: the young person's voice. *Aust N Z J Psychiatry.* 2013;47(10):920–922.
5. Klee D, Latimer E, Stewart J. Creating with, not for: collaborative digital tools for early psychosis. *Psychiatr Serv.* 2019;70(9):766–768.
6. Brett J, Staniszewska S, Mockford C. Mapping the impact of patient and public involvement in health research: a review. *Health Expect.* 2014;17(5):637–650.
7. Barnett P, Mackay E, Matthews H. Co-designed interventions for early psychosis: a rapid evidence synthesis. *BMC Psychiatry.* 2021;21:104.
8. McCabe R, Garside R, Backhouse A. Adolescents' perspectives on early psychosis care: a qualitative synthesis. *J Adolesc Health.* 2020;66(6):697–709.
9. Secker J, Membrey H. Promoting mental health through co-creation: youth narratives in schizophrenia. *Health Promot Int.* 2016;31(2):322–330.
10. O'Brien AM, McNicholas F. Mental health youth advisory groups in early psychosis: models of participation. *Ir J Psychol Med.* 2020;37(4):257–263.