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Folker, Anna P.; Kristensen, Mette M.; Kusier, Amalie O.; Nielsen, Maj Britt D.; Lauridsen, Sigurd M.; Sølvhøj, Ida N.

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Exploring perceptions of continuity of care among people with long-term mental disorders in Denmark

Anna Paldam Folker, Mette Marie Kristensen, Amalie Oxholm Kusier, Maj Britt Dahl Nielsen, Sigurd Mørk Lauridsen & Ida Nielsen Sølvhøj

Abstract
Continuity of mental health care is central to improve the treatment and rehabilitation of people with mental disorders. While most studies on continuity of care fail to take the perspectives of service users into account, the aim of this study was to explore the perceived meanings of continuity of care among people with long-term mental disorders. Fifteen service users participated in semi-structured in-depth interviews. We used template analysis to guide the analysis. The main transversal themes of continuity were “Navigating the system”, and “Connecting to people and everyday life”. While the first theme related to the participants’ experiences of their interaction with the mental health care system, the latter related to their hopes and perceived opportunities for a good life as desired outcomes of mental health care. We conclude that efforts to improve continuity of mental health care should be tailored to the priorities of service users.
Introduction
In past decades, continuity of mental health care has been a central conceptual and operational focal point in efforts to describe and improve the quality of treatment and rehabilitation for people with long-term mental disorders (Freeman, 2002; Ware, Tugenberg, Dickey, & McHorney, 1999; World Health Organization, 2001). In the 1980’s Tessler identified the decentralization of mental health services and the complexity of patients’ illness trajectories as central challenges in the establishment of continuity of care (Tessler, 1986). These observations are still highly relevant more than 30 years later. Research shows that continuity of mental health care is associated with better quality of life, better community function, lower severity of symptoms, and greater service satisfaction among people with severe mental illness (Adair et al., 2005; Ådnanes, Rugkåsa, Ose, Kalseth, & Puntis, 2017).

Several studies have focused on defining and measuring continuity of mental health care (Adair et al., 2005; Freeman, 2002; Pugh & MacMahon, 1967; Sweeney et al., 2016; Tessler, 1986; Ware et al., 1999; Ådnanes et al., 2017). While the concept used to be focused on continuity of care within a hospital setting mainly referring to the need of patients to return to the same ward at readmission (Pugh & MacMahon, 1967), continuity of care in the 1980s became a concept referring to the moment of transition from hospital to outpatient facilities with a focus on discharge planning, rapid transfer and implementation of individualized service plans (Tessler, 1986). Today, continuity of care is increasingly used as broader concept for the cross-sectional and longitudinal organization of mental health care which requires coordination of specialized and cross-sectional services relating to mental health treatment and rehabilitation including social support and employment activities (Freeman, 2002; Ware, Tugenberg, & Dickey, 2003; Ware et al., 1999).

Most contemporary studies take their point of departure in an organizational perspective on continuity of care and the point of view of mental health professionals. Hence, they are mainly
concerned with organizational factors for the improvement of continuity of mental health care, i.e. handovers and coordination in hospitals (Abraham, Kannampallil, & Patel, 2012; Krogstad, Hofoss, & Hjortdahl, 2002; Lewin & Reeves, 2011; Raduma-Tomas, Flin, Yule, & Williams, 2011), and the identification of barriers and facilitators of continuity of mental health care relating to professional boundaries, cultures and intersectoral collaboration (Andvig, Syse, & Severinsson, 2014; Freeman, 2002; McLaren et al., 2013; Ware et al., 2003; Ware et al., 1999).

However, researchers have recently begun to criticize the tendency to define and operationalize continuity of care without taking the perspectives and priorities of service users into account (Biringer, Hartveit, Sundfor, Ruud, & Borg, 2017; Sweeney et al., 2016; Ådnanes et al., 2017). It has been proposed that this deficit has resulted in poor conceptualization of the concept of continuity of care to the disadvantage of people with long-terms mental disorders because of inadequate priority to person-centered care in the practical operationalization of continuity of mental health care (Biringer et al., 2017; Jones et al., 2009; Sweeney et al., 2016).

Although studies investigating the perspectives of people with long-term mental disorders have underlined the importance of continuity of care, these studies were not specifically designed to explore perspectives on continuity of care and thus have only investigated the subject incidentally (Bilderbeck, Saunders, Price, & Goodwin, 2014; Harden, 2005; Kai & Crosland, 2001; Larkin, Boden, & Newton, 2015; Lester, Titter, & Sorohan, 2005; Malmstrom, Horberg, Kouros, Haglund, & Ramklint, 2016; Maassen, Schrevel, Dedding, Broerse, & Regeer, 2017; Rapport et al., 2010; Ryan, Rapley, & Dziurawiec, 2014; Svensson & Hansson, 2006; Whitebird et al., 2013).

Only two recent qualitative studies have focused more specifically on service users’ perspectives on continuity of mental health care. The first study included interviews with ten Norwegian service users at a community mental health center. The study found a discrepancy between aspects of
continuity of care essential to service users and their experiences of actual practice (Biringer et al., 2017). Essential yet sometimes missing aspects of actual practice were related to quality of therapeutic relationship, waiting times, the availability of choice of support options and information on decisions about treatment and rehabilitation. The second study included 31 British service users (Jones et al., 2009). This study found that the experience of continuity of care was very fragile and highly related to levels of satisfaction. The study highlighted a need for supportive and long-term relationships with providers of mental health care and found that such positive relationships could be quickly undermined by a range of factors such as repeated changes of staff and the resulting need of service users to re-tell their stories again and again. The transition at discharge was found to be a key point of vulnerability because of the contrast between the strict routine during hospitalization and the experience of service users that they were left to cope on their own after discharge.

The present study
Previous studies provide valuable knowledge about the priorities of service users in relation to continuity of care and the consequent evaluation of current mental health care. However, they mainly focus on organizational and system-related factors and do not directly investigate the concept of continuity of care in relation to the personal context and everyday life of people with long-term mental disorders. We therefore decided to undertake the following explorative study among people with long-term mental health problems. The aim of the study was to explore the meanings of the concept of continuity of care among people with long-term mental disorders. The study was undertaken to contribute to the emerging research foundation for efforts to tailor mental health care to the needs and priorities of people struggling with long-term mental disorders. In this context, the term “mental health care” is used as an umbrella term that includes care related to treatment, rehabilitation, employment and social services.
The Danish setting of the study

The Danish mental health system consists of three sectors (1) the specialized psychiatric hospitals and outpatient services organized within the five administrative regions of the country, (2) the rehabilitation services, social services, and occupational services across Denmark’s 98 municipalities, and (3) the practice sector including general practice, practicing psychiatrists and psychologists managing the primary health care system and the access to the regional services. As in the rest of Scandinavia, much ambulatory and outpatient care is provided by the municipalities and the district psychiatric centers as an attempt to ease access to care through the provision of services within the local community (Biringer et al., 2017; Gutierrez-Colosia et al., 2017).

A Danish structural reform in 2007 has resulted in the current centralization of specialized treatment in a few highly specialized psychiatric hospitals, a significant decline in hospital admission duration, and a decentralization of outpatient treatment into community mental health care divided between regional services focusing on medical and therapeutic treatment and municipal rehabilitation services focusing on social support and employment-centered initiatives (Kristensen, Sølvhøj, Kusier, & Folker, 2019). While the aim of the reform was to clarify the responsibility between sectors, it has at the same time made it difficult to navigate the system and increased the need to ensure continuity of care across sectors and professional disciplines (Kristensen et al., 2019).

At the moment, there is no exact estimate of the number of people in Denmark receiving multiple services across the mental health system. It has been estimated in 2012 that 1.6% of the Danish population suffers from severe mental disorders, requiring continuous treatment and rehabilitation (Greve, 2012)."
Methods
The study was designed as an explorative, qualitative descriptive study following a semi-structured interview guide (Brinkmann & Tanggaard, 2015; Willis, Sullivan-Bolyai, Knafl, & Cohen, 2016). The design was inspired by a phenomenological approach because the aim of the study was to describe continuity of care by exploring it from the perspective of service users to understand the meanings they attach to the concept (Teherani, Martimianakis, Stenfors-Hayes, Wadhwa, & Varpio, 2015). The study was part of a larger study, which also included a thematic document analysis of external evaluations of 14 national projects on the improvement of continuity of routine mental health care in Denmark from 2009 to 2017. The results of this study will be published elsewhere (Kristensen et al., 2019).

Participants
Recruitment of participants for the study lasted seven months from March 2016 to September 2016. Inclusion criteria were adults (+ 21 years), continuous contact with the mental health care system (hospital- and community-based) within the last three years, geographical variation between urban and rural areas, variation in diagnoses between psychotic and non-psychotic disorders, and variation in terms of level of education, employment, children and partners.

Two strategies for recruitment were used. The first strategy was open recruitment through social media in collaboration with two major Danish NGO’s for people with mental disorders and their families. We used the Facebook-groups administered by the NGOs. This resulted in an initial recruitment of 16 participants. Seven were excluded because they did not meet the inclusion criteria. Five declined due to relapse, lack of energy or concerns about anonymity which resulted in four participants. We also recruited four participants through Facebook-groups of a national peer-network administered by The National Board of Social Services and the national anti-stigma campaign. The second strategy for recruitment was to collaborate with NGOs as well as public and
private organizations specialized in mental health rehabilitation and employment support (five organizations in total). Seven participants were recruited through mental health organizations.

In total 15 participants were recruited for the study; eight women (25-60 years) and seven men (27-53 years). Five participants had a higher education, eight participants had a secondary education and two had a vocational education. Out of the 15 participants, seven were on early retirement pension,\textsuperscript{iii} three were on social security,\textsuperscript{iv} two were on a supported employment,\textsuperscript{v} two had a full-time work and one was a student. The participants came from all over Denmark; 12 different municipalities and three different regions. All participants had a minimum of 3 years of experience within the mental health care system. Seven participants had between 15-30 years of experience within the mental health care system. Experiences with a broad range of services supporting recovery and rehabilitation were included in the study, including mental health specialist services, primary care services, and employment and social welfare services. Six participants were diagnosed with more than one psychiatric disorder and six participants also had co-morbid physical disorders. The mental disorders covered anorexia, bipolar disorder, schizophrenia, paranoid schizophrenia, autism, post-traumatic stress disorder, anxiety, depression, chronical stress and borderline personality disorder.

Four participants had a partner and five had children.

**Procedures**
The interviews were conducted from May 2016 to September 2016 by Anna Paldam Folker, Mette Marie Kristensen, Amalie Oxholm Kusier & Ida Nielsen Sølvhøj. The place of the interview was chosen by the interviewee; the interviews took place either at the National Institute of Public Health (n=5), at the home of the interviewees (n=6) or at the NGO’s (n=4). The interviews lasted 1,5-2 hours and followed a semi-structured interview guide, although the interviewers were also open to unexpected themes and perspectives considered important for the study from the point of view of the interviewees (Brinkmann & Tanggaard, 2015). We were careful not to impose a predefined
concept of continuity of care on the participants in order not to bias the investigation in the direction of specific organizational or system-oriented conceptualizations of continuity of care.

The interview guide was developed based on the aim of the study and informed by previous research on service user perspectives on continuity of care (Bilderbeck et al., 2014; Harden, 2005; Kai & Crosland, 2001; Malmstrom et al., 2016; Svensson & Hansson, 2006). The interview guide included four main sections: (i) Personal experiences relating to navigation in the mental health care system; (ii) Open exploration of the interviewees conception of continuity of care; (iii) Barriers and facilitators for the experience of continuity of care; and (iv) Significant dimensions in relation to successful or unsuccessful illness trajectories.\textsuperscript{vi} The interview guide was tested and adjusted after the first two interviews. Only minor adjustments were made.

During the interviews, interviewees were invited to draw a timeline to visualize when they had received treatment or other rehabilitation services and to recall the various professionals and contact persons that had been involved in their illness trajectories (Carey, 1997). All interviewees accepted the invitation. During the interviews, the timelines were used as steppingstones to focus and to address specific experiences and perceptions relating to continuity of care.

Before the onset of each interview, we carefully explained to the interviewees that their participation was voluntary and that all material would be handled confidentially. All interviewees provided written consent to participate in the study. We audiotaped and transcribed the interviews verbatim (in native language). Field notes were written during the interviews. Transcripts amounted to 400 pages of text. To ensure the anonymity of participants, we have removed all personal characteristics of participants in this paper, hence, we refer to personal data such as diagnosis, geographical regions, age, gender and education/employment only as group data (Morse & Coulehan, 2015).
Data analysis
We conducted a thematic analysis based on interviews, timelines, and field notes by combining an initial explorative approach with template analysis to identify interlaced themes and to structure and summarize the interview data (Crabtree & Miller, 1999; King, 2012). Three interviews were subjected to an initial open coding in the software program NVivo to identify transversal themes and to develop the template for the rest of the coding. Ida Nielsen Sølvhøj did the initial open coding. The resulting themes were discussed at a workshop with Anna Paldam Folker and Mette Marie Kristensen taking account of previous research and refined accordingly. This resulted in a template of ten transversal themes which were used for the coding of the 15 interviews in NVivo. At the workshop the authors carefully discussed data saturation and the need for additional interviews. Based on the discussion we concluded that data saturation was reached around participant number 12. At this point, no substantially new or unexpected themes came up during the interviews. Hence, it was decided that no more than the 15 interviews were needed.

In the subsequent comparative analysis, the thematic codes were analyzed across interviews to refine and explore the details of transversal themes and to systematize the thematic codes accordingly (King, 2012). This led to the identification of two overarching transversal themes or dimensions of continuity of care and the adjustment of the ten initial thematic codes into six more specific subthemes.

Researcher reflexivity
Four researchers with a background in public health and ethics (n=2), and anthropology (n=2) conducted the interviews. During each interview 2 researchers were present. One conducted the interview, while the other took notes and managed the digital recorder. This procedure was adopted as a general safety precaution according to the procedures of the Danish National Institute of Public Health. However, it also enabled the interviewer to fully concentrate on the interviewee and the interview situation, which may have served to enhance the quality of the interview data. Prior to the
study, the researchers carefully discussed preconceptions and professional experiences with the field. We expected that there would be problems in relation to the perceived lack of continuity of care, especially in relation to the transition from hospital to outpatient facilities, but we had no clear prior expectation regarding the perceived dimensions of continuity of care and their relative importance in the context of everyday life.

**Analysis**

The main finding was that the participants employed a very broad and multifaceted concept of continuity of care that transcended previous definitions. We found that care included both formal and informal care from family, friends and colleagues. We also found that continuity of care was a much more fundamental experience that encompassed a sense of continuity between the past, present and future life. Based on the comparative analysis we identified two main transversal themes; “Navigating the system” and “Connecting to people and everyday life”. While the first theme mainly related to the participants’ experiences of their interaction with professionals in the mental health care system and social and employment services, the latter theme related to the experiences of continuity in the participants’ hopes, aspirations and perceived opportunities for a good life as desired outcomes of mental health care. Although separate, the themes were related in the sense that efforts to navigate the system functioned as means to the desired end of participants to attain a healthy life where they were able to connect to people and everyday life. Both transversal themes were prominent in the data material and equally part of participants’ perceptions relating to continuity of care.

During analysis, each transversal theme was broken down into three particularly salient subthemes of continuity and typical subthemes (see table in appendix). Typical subthemes are those in which the core ideas within the theme represented more than half of the interviewees. Each transversal theme and attached subthemes are described below.
Navigating the system

The transversal theme “Navigating the system” concerned participants’ various experiences of their interaction with the mental health care system. Three related subthemes of continuity were found to be important in relation to efforts to navigate the system: Continuity of contacts; Continuity across sectors and professional disciplines; and Continuity between the mental and the physical.

Continuity of contacts

The most dominant subtheme within the first transversal theme was related to participants’ experiences of a frequent change of contact persons or service providers within the system. To some extent a plurality of contacts was seen to be inevitable because of the organization of the mental health system in three different sectors (hospital, community and primary care) and in different disciplines (mental health care, social support and employment support). However, it was a dominant experience that the individual contacts within each sector and within each discipline changed too frequently either because of staff turnover or because of working time regulations.

Some interviewees had had the opportunity to retain the same person from a specific sector or discipline over a couple of years. Although such contacts mainly provided overview and navigation within their own sector or discipline, they were highly valued and conceptualized as a “primary contact person”.

It is my primary contact person who helps me navigate the system. She knows a lot about the various initiatives in the municipality, she knows how things work, and she can come up with ideas, which I have not thought of myself... And then she also has the energy to take the initiative. Sometimes, the issue is [my lack of] motivation. [...] She is a great help - because all these issues are confusing for us “mortals”.

Participants attached great value to the identity of individual contact persons or service providers over time. The provision of stability, knowledge of the individual service user’s story and illness
trajectory, and the possibility of a trustful relationship were judged to be necessary for the process of recovery. The last couple of years I have been in contact with the same psychiatrist. It has meant a lot to me. He knows me, and for me it is of great importance just to know that he is there. […] Stability means a lot – that someone knows you, that you don’t have to start all over again… When you are a patient in the psychiatric system you have to start from the beginning again and again and again.

Most of the service users described the result of changing contact persons as an experience of constantly recounting their story. They described how the lack of stability of individual contacts and service providers made them feel somewhat “alienated” or anonymous in the system because their biographies were unknown by service providers. This was described as a mechanism that served to distance them from their treatment and the process of rehabilitation. The frequent encounter with new service providers were also seen to symbolize an unsecure and unknown environment, which made it difficult to build a relationship of trust. As described by several interviewees, the attainment of trust and stability of contacts and service providers was an ongoing process which ideally integrated past care events with the present and the future, thereby contributing to the sense-making of sometimes chaotic and highly unpredictable illness trajectories.

Among the service users in the study, it was apparent that the ones with a steady and trustful relationship with a primary contact person from one sector or professional discipline, were those who also experienced the greatest motivation and effort for the process of recovery. The availability of a stable and trustful contact person was found to be more important than the specific origin of this person in a specific sector or professional discipline. Moreover, it seemed to be a tendency that the positive effect of at least one stable and trusted contact person from a single sector or professional discipline served to counterbalance the negative effects of the frequent change of individual contacts and service providers from the other sectors and disciplines.
Continuity across sectors and professional disciplines
Another important subtheme within the theme “Navigating the system” concerned participants’ experiences that they in effect were the links between sectors and disciplines. This related to a perceived lack of coordination and exchange of information between sectors and disciplines meaning that different service providers did not necessarily know about the action and treatment plans from other sectors and disciplines.

It was a general impression that health care professionals and service providers from other sectors tried to provide coherent service and care. However, the coordination necessary to ensure continuity of care were often hampered by a variety of obstacles at different levels, e.g. lack of access to information and differences in priorities and decisions due to differences in management, legislation, data systems and budgets. Hence, while some participants experienced coherent and coordinated care within a specific sector or discipline this tended to end abruptly when they crossed sectors and professional disciplines, or when decisions made in one sector (e.g. over medication and treatment regime) influenced possibilities to comply with decisions made in other sectors and disciplines (e.g. concerning employment activities, social skills training or eligibility for social support). Often the participants had the experience of being the only ones who, to some extent, could cross boundaries between sectors and disciplines, and thus the only units for carrying information from one sector and discipline to the other. This was considered very time-consuming and difficult to fit into the narrow time-frames of existing appointments.

Why do I have to be the link? I spend such a short time with them in the first place… So why do I have to explain what kind of work the other person is doing? […] It is also really hard for me to understand….

The provision of information from one sector or discipline to the other was described as a very difficult task for service users because the divisions were seen to be a matter of legal and economic
boundaries which were neither intuitively intelligible nor especially rational from a non-specialist perspective. Several interviewees mentioned that the service providers themselves often found it hard to understand the logic of decision-making and legislative requirements of other sectors and professional disciplines. Moreover, the interviewees often felt that they did not have the resources to understand the system and to correctly identify the various responsibilities, priorities and service offerings of different sectors and disciplines, while they were also struggling with treatment regimes, rehabilitation and personal recovery.

*Often it feels like you are thrown into a dark car [upon discharge from the hospital]. A car that takes you somewhere you don’t know. And then you are thrown out of the car, and you don’t have a GPS, you don’t have anything, so you’ll need to see if you can find the way.*

*That’s how it feels. [...] I really think it’s a jungle.*

It was a general finding that the role as the link between sectors and professional disciplines was described as an insurmountable responsibility that should not be placed on the shoulders of service users.

**Continuity between the mental and the physical**

The final prevalent subtheme within the theme “Navigating the system” involved participants’ various experiences relating to a perceived sharp division between their mental and physical health. It was a general impression that there was a lack of continuity of care between the mental and physical health care system. This was experienced by most of the participants in the study who had various physical symptoms such as bodily pains, high blood pressure, high cholesterol levels and respiratory problems. Out of 15 participants in the study, six had various co-morbid somatic disorders in addition to their mental disorder(s) e.g. heart disease, diabetes, cancer, and lung disease.
The perceived division between the participants’ mental and physical health was described as applying in both areas. Hence, it was a division that was made in the mental health care system as well as in the physical health care system. Especially, service users living with severe co-morbidity, experienced the consequences of this division between the mental and the physical.

At the respiratory medicine clinic, they say it’s very important that I have my sleep apnea machine at night, because it gives oxygen to the heart, and my heart problems can be the result of late treatment. Therefore, it’s important that I use the machine. The thing is, the machine has a long tube, and they won’t allow that at the closed ward, because then I could use it to hang myself. […] They [the mental health professionals] say: “We have to focus on him getting well’, and then I believe they think: “Well, what the hell, we must handle the side effects later on”.

The majority of stories, however, came from bad experiences within the physical health care system where service users felt stigmatized and distrusted as reliable reporters of somatic symptoms. Several interviewees described how they had struggled with health professionals to make them recognize their somatic symptoms as somatic and not as results of underlying mental disorders.

When you have a psychiatric diagnosis, and you are sick, and they can’t figure out what it is, then they state that it is something mental.

I went to have my stomach investigated… but when they found out that I had a history in psychiatry they told me that my physical pain was mentally grounded. Well… it could have been something physical as well. And they actually found something physical when I was finally examined.

Several interviewees reported that their General Practitioner mainly focused on their physical symptoms and consequently referred them to a psychiatrist when the symptoms were mixed
or not exclusively physical. Although interviewees recognized that this could be rational from a specialist point of view, it served to infuse a feeling of stigmatization because mental and physical symptoms were not clearly separated from their point of view, and because they felt a need for health professionals to attend to the totality and joint complexity of their symptoms. *It is very hard for someone like us to be contained in General Practice and to fit into the somatic system. We are extremely stigmatized, because nobody really wants us.*

Hence, the observed obstacles to continuity between mental and physical health care for some seemed to carry a deeper message, i.e. that they were not wanted as persons and were not found to be suitable as subjects of care.

**Connecting to people and everyday life**
The second main transversal theme “Connecting to people and everyday life” concerned participants’ experiences of the derivative effect of continuity of care on their hopes and perceived opportunities for a good life. From the point of view of the participants in the study, the main goal of treatment was to remain continuous with what they considered a normal life. Three related subthemes of continuity were found to be important in relation to the aspiration to stay connected to people and everyday life: Continuity of everyday life; Continuity of family and friends; and Continuity of societal roles. These subthemes all came up when exploring participants’ perceptions relating to the dimensions and importance of the concept of continuity of care.

**Continuity of everyday life**
The most dominant subtheme within the second transversal theme was related to participants’ aspiration to live like everyone else and to be part of the fabric of everyday life. Some participants could relate to the time before their illness and longed for continuity with their former way of life. Other participants, who had very little experience with life without a mental disorder because of early onset of symptoms, expressed a longing for an idea of everyday life and thus an aspiration for
continuity with the kind of everyday life expressed in films and books which was mainly played out in their imagination.

There is this scene in the book "The Stolen Spring", where they sit together and look out of the window and watch how people play or go for a walk. [...] At least, this is what I imagine that people, who are living their lives, are doing. And you do not do that yourself. You feel very alienated. You feel that the only thing that matters, is to be like everyone else, but that’s the only thing you are not. [...] It has always been a major source of frustration that I’m not able to be normal… [...] Normal people are happier. Normal people live their lives the way lives are supposed to be lived. ...It is so difficult to live outside society.

For some participants, the concepts of “everyday life” and “normal people” had an almost ideal status which they characterized by contrast to their own life, by means of dichotomies like happy vs. sad, healthy vs. unhealthy, slender vs. obese; rich vs. poor, and upper class vs. lower class. For these participants, the concepts of “everyday life” and “normal people” were associated with very high and idealized expectations. The longing for continuity of everyday life mainly seemed to be an expression of a longing for a radically different kind of life than the one they lived – a life most of them felt they could never achieve.

Most of the participants in the study described their daily life using metaphors such as “being outside life” or “living in a parallel society”. One of the central mechanisms behind, was described as an inability to exit the “world of the diseased” to enter the “world of the healthy”. Some of the perceived causes of this inability were explained as progressing loneliness and exclusion from the labor market, which will be elaborated in the subsequent two subthemes, but there was also another mechanism at play which in effect served to exclude the participants from everyday life. This was the initiative of Danish municipalities to establish drop-in or day centers for people with mental
disorders to combat loneliness and to provide a safe shelter for networking and social interaction. Some participants described how the establishment of the centers had been a turning point because they offered the opportunity to meet people who shared the same kind of problems and who knew the feeling of being “on the outside”:

*I don’t have friends who are healthy [...] There aren’t many healthy people that can handle the problems we are struggling with, so we stick to ourselves.*

However, several interviewees described how the drop-in or day centers as an unintended side-effect served to exclude them from the rest of society and to reinforce the separation between the “world of the diseased” and the “world of the healthy”. They also described how the process of recovery was gradual and changeable. Hence, while social interaction with other service users was seen to be valuable at an early stage of recovery, the transition to full recovery at some point was seen to require increasing interaction with people without disorders.

**Continuity of family and friends**

Another important subtheme relating to the participants’ aspirations to stay connected to people and everyday life concerned a need to remain in contact with family and friends. Most of the participants in the study reported a progressing loneliness proportional to the duration and progression of their mental disorder. Several interviewees described how their social network had shrunk following the onset of disease.

*In the beginning, when it all fell apart, people called me all the time: “how are you? ...Can we come for a visit?”*. But that came to an end. [...] *At some point, they became tired because I didn’t get any better. ...I think it is actually part of not getting better, that I feel very lonely. I have become lonely because of this.*
Most of the interviewees described the difficulties of their family and friends to relate to their illness. They experienced that their family and friends found it hard to understand the cognitive (and in some cases psychotic) symptoms of mental disorders and to relate to the long-term duration and often discontinuous flow of disease.

_I was having a graduation party for my daughter. But I had hurt my foot, so it was difficult for me to walk. And there was no limit to the interest people took in my foot. They kept asking about it. They even brought coolers and everything. I have been thinking a lot about this incident. It is concrete when I hurt my foot and walk in a strange way. […] But when I try to tell them how I feel tired, how I can’t manage or plan anything, then it is just… then they hate me, they become annoyed, they think I’m stupid, and late, and…_

Several service users of the study described their difficulties in communicating and sharing the part of their lives that were related to their mental disorders. They also described a need to be listened to and to be taken seriously in their own right without their utterances being interpreted in the light of their disease. _The worst thing about having my diagnosis is the scarcity of people who genuinely listen to what I have to say. You really have to fight again and again and keep on trying to communicate… again and again. I wish people would listen... Because I always try to tell the truth. Of course, it is the truth from my perspective. But I’m telling the truth._

Thus, several factors were described in the study as contributing to the progression of loneliness proportional to the development of disease; the long-term duration and discontinuous flow of disease, difficulties in communicating the symptoms of mental disorders and a perceived tendency for the disease to take over as a frame of reference for the interpretation and understanding of the participants.
Continuity of societal roles
The final prevalent subtheme within the theme “Connecting to people and everyday life” concerned the aspirations of interviewees to participate in societal roles. For some this was a matter of continuity with their previous roles in society, while for others it mainly concerned the opportunity to contribute as an equal member of society, although they were not able to hold a full-time job. In both cases, the wish to be connected and thus in continuity with societal roles were crucial for the great majority of participants in the study.

Most interviewees expressed a direct association between their position either within or outside the labor market and their social status in society.

*It has meant the world to me to come back to the labor market. You don’t really understand it until you’re back, when you have colleagues and stuff. How important it is... Because it matters a lot in the Danish society. Working is part of the societal discourse. [...] You do experience a lot of stress and pressure [in the labor market], but it is even more stressful to be outside all the time.*

Several participants described how a position outside the labor market was equivalent to being excluded from society in a more profound sense:

*I have this feeling that being on an early retirement pension amounts to being insignificant to society. It doesn’t matter to anyone whether you get well or whether you get the kind of help that you need.*

Interviewees also described various direct benefits envisaged as resulting from a place in the labor market, i.e. to be part of a social network, to put the mind to rest, and to contribute to something valuable outside their own personal life. However, despite the imagined benefits, most of the
participants in the study described their inclusion in the labor marked as a continuous struggle and a hardship that was very difficult to overcome.

Four interviewees in supported employment or in internships described a very long process of assessment and testing before they were eligible for a job. However, at the end of the process they still found that it did not lead to inclusion in the labor market as they had hoped for. While some of the interviewees who were in the labor market described their position as an “underdog” because they had to do “boring tasks nobody else wanted to do”, others found it hard to become fully integrated in the social community at the workplace, because they felt that colleagues found them either too introvert or too strange. Finally, several participants described as a barrier for inclusion that many workplaces were organized to increase efficiency, which placed a constant pressure on those employees who needed frequent breaks, who worked at reduced times, or who were sometimes absent to prevent a relapse of disease.

No, it [the labor market] hasn’t been a success. And it frustrates me, because I really would like a job. But it must fit my needs and abilities. Since I don’t fit into a specific box, it can be hard to make room for someone like me.

It was a general experience among interviewees that it was difficult for workplaces to accommodate people with mental health problems. This was perceived to be an interrelated matter of social climate, designated tasks and the organization of the labor marked according to principles of maximum efficiency. Thus, the aspirations of interviewees to participate in societal roles through a position in the labor market were described as a “bumpy ride”, where they had to balance between the interests of society, their own interests, and the actual realities in the labor market. The hope and dream of inclusion was for some transformed into a defeat and a feeling of an even more profound exclusion.
Discussion
This is one of the first in-depth studies to systematically explore the perceived meanings of continuity of care among people with long-term mental health conditions. It is the first study to investigate the concept of continuity of care in relation to the personal context and everyday life of people with long-term mental disorders. The main overall finding of the study was that participants employed a very multifaceted concept of continuity of care. We identified two separate transversal themes: “Navigating the system” and “Connecting to people and everyday life”, that were equally important for participants’ conception of continuity of care. The first theme mainly related to the participants’ experiences of their interaction with the mental health care system. The second theme about participants’ aspirations to stay connected to people and everyday life concerned their experiences of the derivative effect of continuity of care on their hopes and perceived opportunities for a good life. From the point of view of the service users, the goal of treatment was to remain continuous with what they considered a normal life - a life that typically revolved around the ability to maintain important social relations and fulfilling valued social roles, e.g. in the labor market.

Compared to our results, earlier studies exploring service user perspectives on mental health care have been almost exclusively focused on one or two provider-oriented dimensions of continuity of care such as doctor continuity related to frequency of appointments and staff turnover (Malmstrom et al., 2016; Svensson & Hansson, 2006) and communication of mental health professionals (Bilderbeck et al., 2014; Kai & Crosland, 2001). Previous qualitative, in-depth studies have also mainly explored service users’ perspectives on the organizational dimensions of continuity of mental health care with little attention to situating the concept of continuity of care in the context of the daily life of service users (Biringer et al., 2017; Jones et al., 2009).

From an organizational perspective continuity of care is a means to improved treatment and rehabilitation, which is considered highly valuable by service users. However, according to our
findings the ultimate goal of service users is continuity of social networks and daily life. For service users, continuity of care in the system is a means to personal and societal recovery, i.e. the possibility to live meaningful lives as equal and included members of society.

This finding supports previous sociological studies on the experience of chronic or long-term illness (Julia, 2003; Karp, 2016). For instance, Karp finds that people with depression often experience a loss of a sense of self, and that much of the depression experience is caught up with interpreting past selves, coping with the future self and constructing a future self that works (Karp, 2016). Thus, from this perspective, continuity of care can be seen as part of a more general process of coping and making sense of mental illness.

In our study, we found that the availability of at least one stable and trustful contact person within the mental health care system could contribute to this process of sense-making of sometimes chaotic and abruptly illness trajectories by facilitating an integration between the past, the present and the future. Sometimes this integration was mainly a matter of reconciliation or adjustment of future aspirations when these were based on very idealized notions of “everyday life” and “normal people”. However, psychological research suggests that the integration between the past, the present and the future may be especially challenging among people with long-term mental disorders because of recollected episodes from the past that are not only difficult and painful but also of crucial significance for the current and past sense of self (Reavey & Brown, 2015).

In our study, we found that drop-in or day centers in spite of good intentions were sometimes found to be divisive because they in effect served to hinder the societal integration of people with long-term mental disorders. This finding supplements a recent study from Sweden about young service users experience of day centers (Gunnarsson & Eklund, 2017). One of the central findings of this
study was the longing for meaningful activities in the community outside the day center and the need for support for engaging in occupations that other young people did.

Regarding the organizational dimensions of continuity of care, the findings of our study to some extent confirm the findings of previous studies. Hence, it is a consistent finding that service users consider stable, supportive, long-term relationships with health care professionals as a key dimension of continuity of care (Biringer et al., 2017; Jones et al., 2009; Malmstrom et al., 2016; Svensson & Hansson, 2006). It is also a recurrent finding that transitions between sectors are key points of vulnerability where the experience of continuity of care is especially challenged (Biringer et al., 2017; Jones et al., 2009; Sweeney et al., 2016).

However, the present study also adds nuance to the organizational perspective on continuity of care. Although previous studies have focused on barriers for intersectoral collaboration in terms of a “cultural divide” between professionals across sectors characterized by different beliefs, attitudes, mutual misperceptions and lack of understanding of different service structures (Andvig et al., 2014; McLaren et al., 2013), our study is the first in-depth study that specifically points to the organizational division between mental and physical health as an obstacle to the perception of continuity of care among service users. In the study, the need for continuity of care across the mental and physical health sector was described by service users as a need for health professionals to attend to the totality and joint complexity of their symptoms. Moreover, the struggle for recognition of somatic symptoms was experienced as an act of stigmatization that carried a deeper message of unworthiness and exclusion from society. The wider health implications of these findings speak their own language. Public health research has demonstrated that people with severe mental illness die 10-20 years earlier than the general population (Laursen, Nordentoft, & Mortensen, 2014). Moreover, it has been documented that most of this excess mortality stems from
the neglect of physical symptoms and physical diseases which are underdiagnosed and undertreated (De Hert et al., 2011; Lawrence, Hancock, & Kisely, 2013).

**Strengths and limitations**
A particular strength of this study is the in-depth interviews with a varied sample of service users with long-term mental health conditions according to diagnosis, age, gender, geographical area, employment, education and civil status. As we experienced, this is a group that is very difficult to recruit because of relapse, lack of energy and sometimes also lack of trust in public authorities. This again, may partly explain why there are so few studies on service user perspectives on continuity of care.

Rigor was ensured in the process of data collection and analysis by using a coding system to list the possible responses from the semi-structured interviews (Morse, 2015). It is a strength of the study that the coding system was based on previous research on service users’ perspectives on continuity of mental health care. Moreover, the coding system was further refined based on an initial open coding of three interviews and a subsequent discussion of themes at a workshop to ensure inter-rater reliability. The open coding was performed to ensure that the study did not impose a predefined and system-oriented concept of continuity of care on the participants. This resulted in a robust template (coding system) which was used to code all interviews of the study. The coding system was crucial as a set of boundary-criteria for the selection of material from the interviews that were related to participants’ perspectives and meanings of continuity of care. Conversely, it served to exclude material regarding illness experiences that were unrelated to continuity of care such as medication, obesity and personal histories.

By conducting semi-structured, individual interviews, we allowed participants to reflect on issues that were important to them at a location of their preference. This promoted a climate of confidence and safety, which may not have been revealed in a survey of a more structured format. Due to the
nature of the personal experiences related to the subject matter, we conducted face-to-face interviews instead of doing telephone or video-interviews, which are unlikely to provide the same degree of confidentiality and mutual trust (Denzin & Lincoln, 2000), as well as observation of non-verbal communication (Harris & Birnbaum, 2015).

We cannot rule out that the adopted strategies for recruitment may have influenced data. The open recruitment strategy through social media may have resulted in a biased selection of participants, although the Facebook-groups contacted were very large and membership was not conditioned on membership in the respective NGOs. The selective strategy for recruitment where participants were handpicked by five different NGOs and organizations specialized in mental health rehabilitation and employment support may also have resulted in a biased selection of participants e.g. participants that were friendlier and more positive towards the system. However, it was not our impression from analysing the data that there were differences between participants recruited in either way. It is the case for all participants that they were motivated to tell their story relating to continuity of mental health care. They all expressed a hope that by sharing their personal experiences and knowledge they would be able to benefit others.

As our findings seem relevant across a varied group of service users with long-term mental health disorders, we believe that they apply to a Danish mental health care setting more generally. To judge from the research literature from other countries we believe that problems and service user experiences relating to continuity of care also prevail elsewhere – especially in Scandinavia and northern Europe with comparable health care systems. We therefore suggest that our findings could be relevant beyond a Danish context. However, further research into these issues seems warranted.

**Conclusion**

In conclusion, our study illustrates that service users’ perspectives on continuity of mental health care add nuance and depth to the more thoroughly investigated organizational and system-oriented
perspective on continuity of care. The service user perspective makes clear that continuity of care in the system is not an end in itself but rather a means to personal and societal recovery, i.e. the ability to maintain important social relations and the possibility to live meaningful lives as equal and included members of society.

The study provides valuable knowledge about service users’ priorities, concerns and values regarding continuity of care that is crucial for the implementation of a personalized approach to the treatment and rehabilitation of people with long-term mental disorders. Such an approach must acknowledge the importance of at least one stable and trusted contact person as an ongoing partner for navigating the system and making sense of mental illness informed by knowledge of service users’ stories and concerns over time. A personalized approach must respond to the need of service users for health professionals that attend to the totality and joint complexity of their symptoms. A personalized approach must also be built on the need of service users to be integrated in society, i.e. to be included in meaningful activities in the community and to gain access to workplaces that accommodate employees who may need frequent breaks, work at reduced times and who are sometimes absent to prevent a relapse of disease. It is also vital that society takes on responsibility for the improvement of mental health literacy among the public. It is necessary for families, friends and colleagues to be able to recognize mental health symptoms, cognitive difficulties, course of disease progression, and their responsibility in the prevention of loneliness and social exclusion among people with long-term mental disorders.

The present study has revealed that service users are very concerned about organizational dimensions of continuity of care. This is not only because of the direct effect of organizational dimensions on the quality and coherence of mental health care but also because the responsibility for their functioning and the consequences of their failure to do so, are implicitly transferred to the service users if not provided by the system. Due to the complexity of the system structured in
different sectors with different legal, economic and managerial frameworks that do not directly communicate, it is a laborious task for service users to assume such responsibility. Ultimately, it may hinder mental health rehabilitation and recovery for some of the members of our societies who need it the most. Our study thus calls for experiments with cross-sectional management, common economies and the adjustment of judicial barriers for the exchange of patient related data as an important precondition for the improvement of continuity of care.

Hence, in multiple ways our findings illustrate that future efforts to improve mental health care would benefit on a social and ethical scale if service users’ perspectives on continuity of care more systematically were translated into practical implementation.

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**Compliance with Ethical Standards**
The study was approved by the Committee on Health Research Ethics of the Region of Southern Denmark. It was also approved by the Danish Data Protection Agency. All procedures performed in the study were in accordance with the ethical standards of the 1964 Helsinki declaration and its later amendments. Informed consent was obtained from all individual participants included in the study.
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1 Administratively, Denmark is organized in 98 municipalities which equals counties in the US. Each municipality belongs to one of the five regions which manage the specialized health sector.

2 This figure has been retrieved from the Danish National Patient Register and refers to admissions to psychiatric hospitals within a period of two years. However, since many patients in need of multiple services within the mental health care system are not admitted to psychiatric hospitals, this number is likely to be higher.

3 Early retirement pension is a social security benefit for people who, because of a physical or mental illness, are unable to work. It is jointly financed by the Danish state and the municipality of the recipient.

4 Social security is financial support for people who cannot provide for themselves and their families. Social security is for persons +30 years. Persons who are below the age of 30, may receive educational support. It is financed by the Danish state.

5 Supported employment entails that the employer must show consideration for the employee because of limited work ability. It is jointly financed by the workplace and the municipality of the recipient.

6 The interview guide is available as supplementary material.

7 The initial template for the coding of interviews contained the following ten themes; concepts of continuity; experience of continuity; significance of continuity; support in navigating the system; communication; professional insight; physical health; medicine; inclusion in society; treatment narratives.

8 The University of Southern Denmark did not have an Institutional Review Board (IRB) at the time of the study.