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Wickedness in Design for People Diagnosed with Schizophrenia

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Abstract. With the digitisation of society, e-health technology increasingly supports new design situations that extend those traditional to Information Systems, and therefore need to be better understood. In design for complex, new and sensitive design situations, it is not possible to apply known methods and solutions without a deeper situational understanding. These design situations are fraught with wicked problems that are contradictory and complex. This paper intends to answer how the wickedness of the design situation when designing e-health technology for people diagnosed with schizophrenia can be understood and what consequences the design situation has for the design process. The paper presents a grounded theory analysis of stakeholder interviews and focus group interviews with people diagnosed with schizophrenia. Four wicked problems are identified: struggle of dependence, contradiction of social interaction, contradiction of trust and counteracting improvement behaviour. The problems are interrelated and have consequences for the design, acceptance, use and user involvement in design of e-health technology for people diagnosed with schizophrenia. The paper also shows the viability of using grounded theory for studying and describing situational wickedness.

Keywords: e-health, wicked problems, wickedness, schizophrenia, grounded theory, design

1   Introduction

During the last decades, technical advances have created a digitalised society. This has in turn expanded the use of digital technology to new situations and user groups; groups that are heterogeneous, and that use digital technology in a multitude of contexts (Iivari et al. 2010). E-health technology is no exception. With the digitalisation of society, e-health technology has to be designed to support previously unsupported user groups. Examples include Tokar and Batoroev (2016) who explore mobile health care for people with depression, Aardoom et al. (2016) who study e-health technology for people with eating disorders and Kowatsch et al. (2014) who study the design of a health infor-

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mation system for reducing childhood obesity. Advances such as these have paved the way for innovative ways to support patients at different stages of their lives.

In order to design digital technology, it is necessary to understand the circumstances in which it is to be designed and used (Hevner et al. 2004). In this paper, the design situation concept includes both the situation in which the information system is designed, as well as its subsequent context of use. It is not possible for one person to have all the necessary knowledge of the complexities of a design situation; it therefore becomes imperative to involve stakeholders and support their communication and collaboration (Arias et al. 2000). When the context of use has been frequently designed for in the past, or is easily relatable, designers can rely on routine in their design actions (Gregor and Hevner 2013). However, in design for new, complex and sensitive design situations such as design of e-health technology with vulnerable users, it becomes more difficult to both study and understand the design situation.

This paper focuses specifically on understanding the situation for the design of e-health technology for people diagnosed with schizophrenia. Approximately 1% of the world's population is diagnosed with schizophrenia (Mueser and McGurk 2004) and have symptoms such as hallucinations, psychoses, apathy, and cognitive impairment (Frangou 2008). Symptoms and treatment for schizophrenia can affect the ability for creative thinking (Andreasen 2000), clear expression of ideas (Schuldberg 2001), as well as social interaction (Couture et al. 2006). The treatment for schizophrenia is typically antipsychotic medication; however, this only has a limited effect (Frangou 2008).

Designing e-health technology for people diagnosed with schizophrenia is an example of a complex and sensitive design situation; it involves encountering contradictory and sensitive problems that affect the design situation, such as paranoia and delusions (Mueser and McGurk 2004), and social stigmatisation (Campellone et al. 2014; Davidson et al. 2004). Furthermore, many in the target user group tend to have limited experience with digital technology (Firth et al. 2015), and cognitive limitations can restrict the ability for verbally expressing (Bowie and Harvey 2006) technology needs. Any process for designing e-health technology for people diagnosed with schizophrenia will have to cope with such problems.

These types of problems that are contradictory, incomplete or have constantly changing prerequisites, are often referred to as 'wicked problems' (cf. Rittel and Webber 1973). Design, which is aimed at iteratively solving problems, is particularly suitable for handling wicked problems (Hevner et al. 2004; Zimmerman et al. 2007). Understanding a wicked problem is also part of understanding its possible solution, since they are only possible to be understood once they have been solved (Rittel and Webber

1973). This makes understanding the wickedness of a design situation critical to the entire design process; it is the essence of the design process.

Understanding the wickedness of designing e-health technology is therefore essential, but at the same time challenging. However, not attempting to do so when it is possible can have negative consequences for the quality of the designed technology. With the current increase of interest in and need for e-health technology for mental health (see, e.g., Firth et al. 2015; Firth and Torous 2015; Gay et al. 2016; O'Leary et al. 2017; Tokar and Batoroev 2016), it becomes particularly important to understand the complexities of the design situation when designing for people diagnosed with schizophrenia.

Therefore, this paper intends to answer the questions: *When designing e-health technology for people diagnosed with schizophrenia, how can the wickedness of the design situation be understood, and what consequences does the design situation have for the design process?*

The aim of the paper is to explore this wickedness, and therefore a grounded theory analysis is proposed to understand the wickedness of the design situation. The purpose is both to focus on the nature of the wickedness and its consequences for design, as well as to discuss the applicability of the grounded theory approach to exploring wickedness in design situations.

2   Schizophrenia

Symptoms of schizophrenia can be positive (in the sense that they constitute an addition of abnormal symptoms and behaviours), negative (constituting a lack of normal symptoms and behaviours), or cognitive (Frangou 2008; Mueser and McGurk 2004). These symptoms are manifested to a different degree among individuals (Frangou 2008). Positive symptoms include delusions and hallucinations (Frangou 2008); in essence a loss of contact with reality (Mueser and McGurk 2004). Negative symptoms include flat affect, social withdrawal and reduced speech (Frangou 2008; Mueser and McGurk 2004). Many also have cognitive impairments, such as problems with attention, learning and memory, illogical thinking, confusion, delusion and strange linking of thoughts (Mueser and McGurk 2004; Schuldberg 2001; Wilder-Willis et al. 2002). There is no objective, diagnostic test for schizophrenia; the diagnosis is made based on a criterion-based system where other illnesses are excluded (Frangou 2008). Due to the different nature of the illness, there are subsets of schizophrenia, for example, paranoid schizophrenia and disorganised schizophrenia (Frangou 2008).

There is no cure for schizophrenia, only ways to cope with the illness. Most return to a functioning life after the first onset, although approximately 10% never do (Frangou 2008). The outcome appears more promising in developing countries than in developed countries (Frangou 2008); there are indications that this may be connected to the mode of treatment. The primary treatment in developed countries is antipsychotic medication that primarily treats positive symptoms (Frangou 2008). Antipsychotic medication does not appear to improve cognitive function, and even though other symptoms improve, these cognitive symptoms tend to remain (Wilder-Willis et al. 2002). Psychosocial treatment such as supported employment and social skills training has been found to improve the ability to handle the symptoms (Mueser and McGurk 2004).

The social and emotional limitations that people diagnosed with psychotic disorders, such as schizophrenia, experience can often lead to isolation (Castelein et al. 2015). Social support has been found to benefit people diagnosed with schizophrenia (Castelein et al. 2008; Chinman et al. 2014; Davidson et al. 1999; Lloyd-Evans et al. 2014). However, due to both social stigma and symptoms such as reduced vocal ability, lack of motivation, and difficulties with memory and concentration, it is difficult for people diagnosed with schizophrenia to organise social support themselves (Castelein et al. 2015). Increasingly, people diagnosed with schizophrenia are turning to social media not specifically designed for their needs, risking low quality support and being identified as an individual with such an illness and its associated stigmatisation (Naslund et al. 2014). People diagnosed with mental health conditions in younger generations are also more likely to use social media to build friendships (Gowen et al. 2012).

E-health technology for mental health has in recent years been gaining more attention (Firth et al. 2015; Firth and Torous 2015; Gay et al. 2016; O'Leary et al. 2017; Tokar and Batoroev 2016). For example, Melling and Houguet-Pincham (2011) study e-health technology for people who are experiencing depression, O'Leary et al. (2017) involve individuals with mental illnesses to design technology for peer support, and Lederman et al. (2013) design online social therapy meant to detect warning signs among young people with psychoses. Each of these cases illustrates a complex and sensitive design situation, and the necessity to understand the design situation as part of the design process in order to adapt both the design process and the e-health technology.

Studies have shown high feasibility for using e-health technology, and specifically mobile health technology for supporting people diagnosed with schizophrenia (Firth and Torous 2015). E-health technology for mental health has shown promise for reducing the health care barrier, dealing with stigmatisation, and individualising treatment (Tokar and Batoroev 2016). However, while several studies look at the use of e-health technology (e.g., Firth et al. 2015; Firth and Torous 2015) and social media for health

support purposes (e.g., Gowen et al. 2012; Naslund et al. 2014), studies on the design of such technology are scarcer.

People diagnosed with schizophrenia are seldom involved in design activities; symptoms such as cognitive limitations (Bowie and Harvey 2006) for example in verbal expression (Andreasen 2000) combined with social stigmatisation (Imhoff 2016) limit the possibilities of their involvement. Symptoms of schizophrenia can, for example, impair the ability for creative thinking and imagination (Andreasen 2000). There are indications that people diagnosed with schizophrenia are more likely to jump to conclusions (Dudley et al. 2016; Moritz et al. 2006). Socially, people diagnosed with schizophrenia can have difficulties maintaining employment and regular societal functioning (Couture et al. 2006) and tend to use passive coping strategies, meaning that they tend to withdraw (Wilder-Willis et al. 2002). Symptoms such as these can make the design of digital technology for and with people diagnosed with schizophrenia more complex than for people who do not experience such symptoms.

However, other vulnerable user groups have been involved in design under different circumstances, for example, children with a history of cancer (Lindberg et al. 2017), people with dementia (Branco et al. 2017), women with breast cancer (Skeels et al. 2010), homeless (Le Dantec et al. 2011), as well as people with aphasia (Wilson et al. 2015). These studies encountered challenges with for example ethics, user access, and adaptation of techniques for user involvement. Approaches to user involvement, such as co-design and participatory design, thus encounter many challenges but also many opportunities for involving users who are considered vulnerable (Vines et al. 2017).

3   Wicked problems

When designing e-health technology for people diagnosed with schizophrenia, the design situation contains unique complexities and sensitivity, for example related to the symptoms of the illness and social stigmatisation. The concept of wicked problems was initially described by Rittel (1972) and Rittel and Webber (1973). The difference between typical, simple problems with established procedures and wicked problems, is that wicked problems do not have clear solutions, it is not always possible to know when or if they have been solved, and they are not possible to delineate and clearly define (Rittel and Webber 1973). Social problems (Rittel and Webber 1973) and problems approached using non-linear design processes are usually of a wicked nature (Farrell and Hooker 2013). In fact, all problems in design, except those taken on by routine design, are wicked problems (Hevner et al. 2004). There is no single right or wrong solution (Nelson and Stolterman 2003); the solution to a wicked problem lies

in the world view of the solver (Rittel and Webber 1973), in this case the designers and users (Buchanan 1992).

In the attempt to solve wicked problems, all actions taken will affect the surrounding context and there is thus no way to undo mistakes (Rittel and Webber 1973). Therefore, it is important to reduce the possibility for mistakes. Yet, wicked problems cannot be sorted into predefined categories, nor are there any predefined ways of solving them; all wicked problems are unique (Rittel and Webber 1973) and must be handled in a manner appropriate to their complexity, ambiguity and uniqueness, with a focus on achieving a desirable outcome instead of a clear problem solution (Nelson and Stolterman 2003).

The collaboration between different people in design is suitable for tackling wicked problems (Hawryszkiewycz 2014) and the iterative, practice based approach to design is considered appropriate for handling wicked problems (Buchanan 1992; Farrell and Hooker 2013; Hevner et al. 2004). Designers who approach a wicked problem invariably, due to the nature of the problem, have to face design situations with little prior work that call for new and diverse skills (Howard and Melles 2011).

McCall and Burge (2016) critically examine the theory of wicked problems and emphasise four amended features. Firstly, they highlight that there is a cause and effect relationship between wicked problems, and that identifying cause and effect relationships is the main focus in handling them (McCall and Burge 2016). Secondly, they revise the notion put forward by Rittel (1972) that trial-and-error cannot be used when solving wicked problems. This relates to their third conclusion, that previous projects can inform future projects, which was also refuted in Rittel and Webber (1973). Fourthly, they conclude that wicked problems always have unforeseen consequences, and this capricious nature of wicked problems is what causes the primary difficulty of solving them (McCall and Burge 2016).

The literature suggests that wicked problems can be conceptualised along a scale, with problems varying in degree (Farrell and Hooker 2013) or along a spectrum of wickedness (Burge and McCall 2015). One example of such a gradation is the concept of the so-called super wicked problem, which has additional features that increase its wickedness in relation to regular wicked problems (Levin et al. 2009). Viewing the concept as a spectrum indicates that there are certain problems that are more wicked than others, and that certain design situations can have a higher level of wickedness.

Research within Information Systems (IS) and related design fields has previously tried to approach wicked problems, for example by using game design to increase awareness of climate change (Coulton et al. 2014), by using participatory design to design sustainable communities (McGinley and Nakata 2012), and by using user-cen-

tred design tools such as personas to reduce ICT4D project failures (Peter 2015). Dealing with complex problems requires that the designer considers the whole as well as the parts; that is, to not only focus on the specificities of the identified problem but also on the nature of the circumstances within which the problem resides (Nelson and Stolterman 2003). Instead of oversimplifying, it is important to consider the problem on different levels, systemically (Nelson and Stolterman 2003). Familiarizing oneself with the design situation is also an important step in better utilizing the empirical material (Alvesson and Kärreman 2007). Wicked design problems have for example been identified as part of the design of health-promoting resources for children cured from cancer (Wärnestål et al. 2014). This paper is a step towards creating an understanding of the wickedness of the design of e-health technology for people diagnosed with schizophrenia.

4   Method

This paper employs a grounded theory analysis to answer how the wicked problems in the design situation of e-health technology for people diagnosed with schizophrenia can be understood and what consequences this has for the design process. The approach was considered appropriate because it is a way to make sense of stories told by interviewees, a way to stay close to the empirical material, and to learn about the situation under study (Charmaz 2006). Grounded theory was first introduced by Glaser and Strauss (1967) and has since developed in different directions. This paper relies on the work of Charmaz (2006) as a foundation for the employed methodology. Charmaz (2006) emphasises that theories are not found, but constructed by the researcher in an interpretive process of analysis. Grounded theory can be successfully combined with design research, and one use of performing a grounded theory analysis is in the early stages of a design process, in order to gain a systematic and deep understanding of the design situation and problem area (Gregory 2010), as in this case.

Grounded theory has been increasing in use within IS, as it is considered useful for describing processes and phenomena (Hughes and Jones 2003). However, the existence of myths regarding the nature of grounded theory has been considered the cause of its misuse or lack of use (Urquhart and Fernandez 2006). These myths include the misconception that literature cannot be studied before performing a grounded theory analysis (Urquhart 2001; Urquhart and Fernandez 2006). Instead, literature should be studied beforehand, but not in order to integrate into the yet unidentified theory (Urquhart and Fernandez 2006); it should be used strategically (Charmaz 2006). In this paper, the intent was not at the onset of the analysis to identify wicked problems. However, the

results that emerged from the application of grounded theory showed many sensitive and contradictory circumstances within the studied design situation, and these were then identified to be wicked problems. The literature on wicked problems was thus incorporated after the analysis was performed.

4.1   Study design and analysis

The empirical material included in this study consisted of: (1) semi-structured stakeholder interviews, four with relatives of people diagnosed with schizophrenia and three with medical professionals; and (2) two focus group interviews, each with two people diagnosed with schizophrenia. The focus group interviews were part of the first of three design workshops in a larger research project. The empirical material consisted of a total of 540 recorded minutes.

The individual and focus group interviews were all transcribed and coded line-by-line using open coding. In accordance with the recommendation by Charmaz (2006), the codes were formulated closely to the original wording; this close attention to early coding resonates with the concept of grounded theory, which highlights a closeness to the empirical data. The open codes were then grouped into categories using focused coding. Constant comparison between data, codes and categories is considered to be the core to grounded theory (Charmaz 2006). The open and focused coding was therefore done iteratively, and each new code was compared with the existing codes and categories. Category identification was done by using the most significant codes as a starting point. Examples of categories include *depending on others*, *having illness awareness*, and *using strategies*.

The relationships between the identified categories were then axially coded. Axial coding serves to make sense of the relations between categories and subcategories, and return a holistic perspective on the data (Charmaz 2006). This was done using analysis software visual mapping functionality. For example, the category *depending on others* related to the category *fearing* since fear affects the ability to depend on other people. It was at the axial coding stage that the wicked problems were identified in the conflicting nature of the categories. A total of 58 memos were written throughout the analysis process. Memos are an important part of a grounded theory analysis as they function as a tool for analysis, theory creation and idea generation (Charmaz 2006). In this paper, the memos were important for recording insights and interpretations throughout the analysis, for example to record reflections on the contradictions that emerged.

The result presented in this paper is only part of the results from the grounded theory analysis. As the result was rich and diverse, it became more suitable to present it over

the course of more than one paper for the sake of clarity. This paper relates to the entirety of the result related to wicked problems, while other aspects of interest emerged at the later theoretical coding stage, in accordance with a grounded theory analysis (Charmaz 2006). The result from the grounded theory analysis was thus more extensive than the wicked problems described in this paper. The analysis process is summarised in table 1. The steps of the analysis were performed iteratively throughout the analysis process.

Activity	Outcome	Examples
Transcription	Verbatim transcriptions of the individual and focus group interviews.	N/A
Line-by-line open coding	921 codes formulated closely to the original wording.	being unsuspecting, having few requirements, being afraid of theft, having to ask for help, fearing relapse, fearing men
Focused coding grouping	26 categories based on the most significant codes as starting point.	depending on others, having illness awareness, using strategies
Axially coded relationships	Mapping of conflicting categories. 4 wicked problems were identified.	*depending on others* relates to *fearing* since fear affects the ability to depend on others
Memo-writing	58 memos for recording insights and interpretations.	"When depending on other people, you really need to trust them. But at the same time, schizophrenia somestimes involves paranoia. Yet some people are also too trusting. This is contradictory."

Table 1. Overview of the analysis process.

4.2 Participants

The participating stakeholders were four parents of people diagnosed with schizophrenia, one activity coordinator, one psychiatric nurse, as well as one assistant nurse working with housing support. The participating users all had a diagnosis of schizophrenia, were between 45-51 years old, and had been treated for more than 10 years. They all relied on support from medical treatment and were on a disability pension. In total, four people diagnosed with schizophrenia participated in pairs in the focus group interviews. All participants' and their relations' names have been changed. There was no relationship between the participants. Table 2 shows an overview of the participants and their roles.

Participant role	*Participants*
Parent	The mother of Jack The father of Brock The mother of Carl The mother of Dani
Medical professional	Alfred, activity coordinator Benjamin, psychiatric nurse Chris, assistant nurse
User	Frank Scott David Angela

Table 2. Overview of the research participants.

4.3 Research setting

The research in this paper was performed as part of a research project aimed to design Digital Peer Support (DPS) for people diagnosed with schizophrenia. Peer support is a type of social support that connects people with shared experiences in mutual support based on a shared understanding and empathy (Mead et al. 2001; Solomon 2004). A well-known example of peer support is Alcoholics Anonymous. DPS has shown similar

benefits as face-to-face peer support, for example in the treatment of mental health (O'Leary et al. 2017), and additional possibilities for connecting peers regardless of time and geographical constraints. Technical developments have further extended the possibilities for enhancing accessibility (O'Leary et al. 2017) and use of social interaction afforded by social media (Obar and Wildman 2015).

The data collected for this paper was part of an early part of the project, which focused on understanding the design situation and prerequisites for design. Later stages of the project included participative design workshops together with people diagnosed with schizophrenia, which involved them actively in design, prototype development and evaluation. As an outcome of this design process, a prototype of a DPS service for people diagnosed with schizophrenia was created. Details on the participative design process are published in Lindberg et al. (forthcoming).

4.4   Ethics

The project that this research is part of was approved by the regional ethical review board (Dnr 2011/267). When the design situation is sensitive, as in this paper, there is a risk of harming the participants. The participants' wellbeing may be affected, and if the information on their participation would be made public, they can suffer social consequences due to the stigmatisation of mental health illnesses (Campellone et al. 2014). During the interviews, two relatives of people diagnosed with schizophrenia expressed concern that if their participation became known, it could have a negative effect on their children. To ensure anonymity, all participants' names have been altered, and any information that might lead to their identification has been excluded.

Furthermore, one of the researchers who participated in the focus group interviews had a background in nursing and many years experience of supporting people diagnosed with schizophrenia. As the focus group interviews were only the first in a set of three workshops, she maintained contact with the participants between and after the time of the workshops, in order to ensure their wellbeing.

5   Research outcome

This section presents the results from the grounded analysis. Table 3 summarizes the identified wicked problems that are described in detail in the remainder of this section.

Situational wickedness	*Description*
Struggle of dependence	Living with schizophrenia causes dependence on others. The treatment system does not support independence, and some struggle with the collective treatment. People diagnosed with schizophrenia also tend to use little digital technology, leaving them outside the increasingly digitized society, deepening their dependence.
Contradiction of social interaction	People diagnosed with schizophrenia lose most meaningful social connections yet acquire many medical contacts. This, along with stigmatisation, makes interaction impersonal and people are often lonely despite much social interaction. Medical contacts enhance social behaviour that serves to alienate meaningful relationships.
Contradiction of trust	Due to being dependent, people diagnosed with schizophrenia have to trust others. However, the rationale behind trust is sometimes contradictory. People in presumably trustworthy positions, such as medical personnel, may be mistrusted, while strangers are trusted. Trust also affects digital acceptance. Fear of technology and consequences of previous naïve use can reduce trust of technology.
Counteracting improvement behaviour	Some behaviour directly counteracts possibilities for improvement. People diagnosed with schizophrenia tend to use avoiding coping strategies and isolating behaviours, increasing their loneliness. Balance tends to disappear.

Table 3. Summary of the identified wicked problems.

5.1 Struggle of dependence

The analysis indicates a struggle between being dependent and wanting to lead an independent life. The illness usually manifests itself in your twenties, when quite abruptly something starts to feel wrong, and normality is lost. Medical professional Alfred describes it as:

The withdrawal [from society] starts because something happens in your body or your head that you can't really… that doesn't feel right.

And Frank says that when he fell ill:

It didn't add up for me at all, my damn voices.

However, the memory of a normal life still exists and is something that the users in this study expressly want. Angela describes how she attempts behaviours and activities that the group home personnel do, because it seems healthy:

The staff at the group home work out a lot and that and… /…/ they feel well so I thought that I will do the same.

Similarly, Brock's father describes how it gives his son, who has recovered enough to maintain a regular job, pleasure in life to be able to buy things like everyone else. Nevertheless, Alfred explains that the treatment system does not have the goal to create a normal life for people diagnosed with schizophrenia. Instead, the system treats the care recipients collectively, removing independence. David describes how he is no longer allowed to work by the Social Insurance Agency, despite previously being able to maintain a part-time job. Jack's mother describes her son's group home as 'storage', and psychiatric nurse Benjamin describes his patients as being 'preserved':

The illness becomes a kind of formalin. You get stuck where you become ill sometimes, and there is little new added.

Frank says that in some ways he felt better when he lived on the streets, because he was able to make his own decisions.

People diagnosed with schizophrenia are described by the participants as having no or few hobbies, and even fewer that they can afford. As a result, they are dependent upon others to be activated. Dani's and Jack's mothers, psychiatric nurse Benjamin, as well as David all describe a need for other people to help with activation. However, the care system does not currently provide adequate support for this.

Furthermore, the stakeholders express that people diagnosed with schizophrenia use little digital technology. This is due to a combination of factors. For one, the user group is to a large extent on disability pension and therefore cannot afford digital technology. Frank and Scott both own smartphones, but explain that the majority in their situation

do not, and that they have only been able to buy them since mobile subscriptions became more affordable. Medical professional Alfred tries to help:

> We try to offer different kinds of study groups, and it's often computers that is being requested. So it's not about not being interested, but about not having the opportunity to.

Additionally, psychiatric nurse Benjamin describes issues with cognitive ability when learning how to use digital technology:

> Patients that are chronically ill with a psychotic illness and have recurring periods of symptoms get a kind of cognitive impairment as well. /…/ They may have a more difficult time to take it in.

The stakeholders express a need to increase digital technology use among this user group. Jack's mother describes it as this group being left out, and therefore also ending up outside of society. As a result, they become even more dependent. Nevertheless, this is a generational issue. Several stakeholders agree that with the coming generations, some of the described issues relating to the use of digital technology will no longer be valid. However, it will still be many years that these issues stay relevant.

5.2   Contradiction of social interaction

The analysis further shows a contradiction in the social interaction of people diagnosed with schizophrenia. People diagnosed with schizophrenia are described as exceedingly lonely. For example, assistant nurse Chris says that his patients' social lives become minimal after becoming ill, Carl's mother says that her son has lost all former friends and made no new ones, and Jack's mother says that her son's friendships have been forced on him, as they are all people who live in the same group home. Medical professional Alfred summarises:

> When the person in question falls ill most contacts disappear. You have your parents left, and maybe some childhood friend who gets in touch once in a while, mostly because they feel guilty.

Nevertheless, despite the lack of close relationships, people diagnosed with schizophrenia meet a great number of people in their everyday lives. The majority of people they

meet are medical professionals. Many have weekly visits from nurses, housing support help with everyday tasks, and most have to meet an assistant nurse daily to take their medication, as they are not allowed to handle it themselves. Yet, this is only superficial social interaction. Frank describes the isolation as the worst part of the illness:

> The hardest part of the illness was the isolation, the loneliness in the beginning, at first when you were lying at home.

Scott says that there cannot be too much social interaction. Yet both Frank and Scott agree that it is easier to interact with others who have a similar understanding of the illness. Scott wants more information from self-experienced online, and Frank chooses friends that have similar experiences.

Another issue that is raised is stigmatisation of the illness. Psychiatric nurse Benjamin explains that the diagnosis itself can act as a deterrent, something that Frank experienced when he tried telling people around him about his experiences. Both Brock's father and Carl's mother express concern about revealing their names, as they fear that their sons will be negatively affected if the interviews can be traced back to them.

Further, people diagnosed with schizophrenia can sometimes engage in alienating behaviours that may strengthen that stigmatisation. For example, assistant nurse Chris describes how some of his patients have lost any chance to befriend their neighbours because they have tried to borrow money from them in the past. Further, Frank explains how he has had to learn that the kind of behaviour his nurse and care staff want is not acceptable elsewhere:

> It's mostly medical personnel and those who have experience… that get to hear some things. /…/ The friends… they just think that you're insane and that it can't be right, you know.

Since the people he mostly meets, medical professionals, enforce a behaviour that alienates his other relationships, he has had to adapt his behaviour in order to maintain the friendships that he values.

5.3 Contradiction of trust

From the analysis, a contradiction emerged in how people diagnosed with schizophrenia trust others. Due to their dependence upon others, people diagnosed with schizophrenia have to place a great deal of trust in the people they are dependent upon.

However, people diagnosed with schizophrenia often have misplaced suspicions, and can sometimes be paranoid. Jack's mother describes how he does not trust the staff at his group home:

> He experienced chest pains he told me one morning last week or a fortnight ago… And he hadn't said anything to the staff. He doesn't have that much confidence in them.

At the same time, she describes her son as being too trusting of strangers:

> He thinks good of people and… he gets robbed. That's why he doesn't have an ATM card anymore. /…/ They emptied it for him. So he is a bit unsuspecting-has become after the illness.

The other stakeholders describe similar behaviours in their children or patients. Dani's mother says that her daughter always wants to be able to keep an eye on any visitors, even when it is her mother. Brock's father describes his son as being kind to the verge of wanting to buy friends with gifts. Angela tells us of how she has repeatedly been robbed of large sums of money.

People diagnosed with schizophrenia are a group of people vulnerable to fraud and theft, yet one symptom of schizophrenia is paranoia, as Jack's mother describes:

> He called my house… and accused me of having started the Second World War /…/ and he couldn't eat because the food was poisoned…

Trust and distrust appears to be misplaced and irrational. Yet people diagnosed with schizophrenia have to rely on and trust other people to help them manage their everyday lives. Dani's mother describes it as:

> They should actually have a real personal assistant all the time, really.

Irrational fear also affects digital technology acceptance and use. Jack's mother describes how she has to take care of his finances because he refuses to own as much as an ATM card. He flushed his mobile phone down the toilet due to his fear of technology. Similarly, Scott says that he has never dared use Facebook because he is afraid that everyone in the world will see his information.

Furthermore, there are also risks with technology use. Carl's mother describes how her son used online information to convince himself of not taking his medication:

> At one point in the period of his illness he found some contacts online, or information, and he used that to show me, "Look here, this is the way it is, this is what they are putting me through." And it got worse from that.

Some stakeholders describe negative consequences such as posting rants online during a psychosis for everyone to see, and assistant nurse Chris describes how one of his outpatients had their credit card emptied while playing an online game. This kind of naïve use, combined with being vulnerable to fraud and theft, can thus cause an increase of fear of digital technology, and reduce its use.

5.4   Counteracting improvement behaviour

The results further indicate that people diagnosed with schizophrenia can behave in ways that counteract their improvement. The participants, for instance, describe avoiding strategies to cope with the illness. Jack's mother says about Jack:

> He had this in himself that he runs- or he used to run away.

Frank also describes an avoiding behaviour. He found it easier to live on the streets than to be medically treated because there he could flee from his problems. He eventually realised that he could not run away from the voices.

Another behaviour that the participants describe is an isolating behaviour. Medical professional Alfred says that people with psychoses often tend to isolate themselves, and Dani's mother describes her daughter as exhibiting both avoiding and isolating behaviours:

> And it's not easy to help her, because she doesn't want to either. "I have to cancel," she says. "I can't." /…/ She just isolates herself in the apartment.

The stakeholders describe employment as particularly important for improvement. Carl's mother believes her son's job to be one of the main reasons why he is better, and psychiatric nurse Benjamin expresses that access to meaningful employment would be key in treatment:

… there are sometimes more medical solutions that there need to be. If you would have a meaningful occupation and something that distracts you from the symptoms of your illness, I think there would be a lessened need for medication compared to what is being prescribed today.

There is a constant struggle to maintain a balance in life. Having schizophrenia means losing normality, and the illness is often described as going through periods. David describes himself as currently going through a rough period:

I am in a period when I don't think it's fun to do things and… /…/ I'm in a difficult period that is maybe quite hard to get out of too.

He describes his days as being spent mostly in bed. In contrast, he describes a period when he felt better:

I got out of bed at a normal time like… around eight then… and then I had chores and stuff. I was on my father's computer a lot… and downloaded music…

In contrast, Angela has the opposite problem of tending to do too much:

And then I worked out and went swimming on the same day, on Mondays, and Tuesdays, and Wednesdays, and Fridays and Saturdays. /…/ But my body spoke up, because I did too much, so I became ill instead.

Alfred, one of the medical professionals, describes this lack of balance as being common among people diagnosed with schizophrenia:

Those basal functions are somehow affected in this. Either you fall behind or you sort of… overdo it in some way. That you stodge and… things like that. The normal sort of goes away.

Illness awareness also affects the ability to cope and the ability to maintain a meaningful everyday life. Several of the stakeholders describe how their children or patients do not want treatment simply because they do not think of themselves as ill. Brock's father describes his son's lack of illness awareness and its effects:

We tried to get our kids – our grown kids – to be interested in something, so we had some activities and things, but he… he didn't consider himself ill so he didn't go to things like that.

In order to improve, it is important to maintain a balance. The avoiding coping strategies and isolating behaviours that are exhibited by people diagnosed with schizophrenia thus directly counteract the activities that would help them improve their lives.

6   Discussion

This paper studies the wickedness of the design situation when designing e-health technology for people diagnosed with schizophrenia. The analysis identified four wicked problems. Thereby, this paper demonstrates the viability of a grounded approach to study the wickedness of a design situation with the intent to gain situational awareness in complex and sensitive design situations. In this section, the wickedness and its consequences for design will be discussed, along with the approach to studying it.

The identified wicked problems are interrelated, and not mutually exclusive. As with any wicked problem, they are indefinable, untestable, and unique to the situation (Rittel and Webber 1973). For example, the wicked problems *struggle of dependence* and *contradiction of trust* are related in that dependence causes a need to trust. If people diagnosed with schizophrenia had not been dependent upon others, they would not be contradictorily trusting. However, it is equally possible that if there had not been a contradiction of trust, there would not be a struggle of dependence. As such, the wickedness of this design situation is not a single problem, but a chain of interrelated wicked problems that together make up the wickedness of the design situation.

The wickedness that this paper has explored consists of struggles between dichotomies, or opposite forces, such as dependence versus independence. This is an important part in the discovery of how to design e-health technology for people diagnosed with schizophrenia. As Buchanan (1992) explains, wicked problems stem from the nature of the design subject; wicked problems are wicked because design implies discovery. In this case, each identified wicked problem presents consequences for the design of e-health technology for people diagnosed with schizophrenia.

Firstly, the wicked problems present consequences for involving users in the process of designing e-health technology. The wicked problems *struggle of dependence* and *contradiction of trust* show that the use of digital technology is low among the target user group for reasons of economy, cognitive ability and paranoia. While this is in part a generational issue and the use of for example mobile technology is increasing among

people diagnosed with schizophrenia (Firth et al. 2015), many still remain in economical hardship and cannot acquire expensive digital technology. Cognitive limitations and paranoia aimed at digital technology also restrict the possibilities for learning how to use this technology. Furthermore, the symptoms of schizophrenia can be diverse (Frangou 2008), making it difficult to predict or understand the challenges of user involvement in advance. Literature on participatory design and co-design with other vulnerable user groups for example highlight challenges related to ethics, user access and flexibility in design techniques for involvement (Culén and van der Velden 2013; Lindberg et al. 2017; Wilson et al. 2015).

As a consequence, a design process that aims to involve people diagnosed with schizophrenia has to support the participants in expressing their technology needs. Culén and van der Velden (2013) outline similar conclusions from involving elderly in design, and surmise that users who cannot express their needs also cannot be representative of the user group. In this case, the users' abilities for expression are further complicated by their limitations in social skills and cognitive ability. People diagnosed with schizophrenia may have affected verbal fluency (Tsakanikos and Claridge 2005) and cognitive limitations (Bowie and Harvey 2006), and the *contradiction of social interaction* shows that the social behaviour enforced by medical contacts serves to alienate others in social interaction. The *struggle of dependence* also shows that users are treated collectively, and therefore, individual expression can be a challenge. Any design process that aims to involve people diagnosed with schizophrenia in design thus has to be flexible and support the participants in their social interaction and expression of individual needs.

Furthermore, as the wicked problem *counteracting improvement behaviour* shows, people diagnosed with schizophrenia tend to use behaviours that counteract possibilities for improvement, and they tend to use avoiding coping strategies (Wilder-Willis et al. 2002). This presents a risk for user involvement as users may choose not to participate despite the potential benefits that participation presents.

Secondly, the wicked problems present consequences for the design of e-health technology. For example, the wicked problems *contradiction of trust* and *contradiction of social interaction* indicate that e-health technology for this user group would need to enforce healthy social interaction, build trust and protect users from harm; at the same time, these goals are particularly difficult to achieve due to the identified contradictions.

There is potential in e-health technology for reducing the stigma of mental illness (Tokar and Batoroev 2016), and this study further shows that there is need to reduce the loneliness felt by people diagnosed with schizophrenia. Nevertheless, the wicked problem *contradiction of trust* emphasises that people diagnosed with schizophrenia can be suspicious of digital technology, and refrain from using it despite possible benefits.

This means that any e-health technology aimed at people diagnosed with schizophrenia would have to be transparent enough to create trust.

Additionally, some users experience negative consequences from previous use. Similarly, Naslund et al. (2014) focus on one aspect of this, that is, the social consequences that can occur from exposure and stigmatisation on social media. A consequence for design would be the necessity to allow anonymity. At the same time, the *contradiction of trust* shows that fraud and misinformation can be harmful. A consequence for design, which contradicts that of anonymity, is to moderate information and interaction. These contradictory consequences for design would need to be handled in the design of e-health technology for people diagnosed with schizophrenia.

Thirdly, the wicked problems present consequences for acceptance and use of the e-health technology. The lack of technology use shown in *struggle of dependence* and the paranoia aimed at technology shown in *contradiction of trust* naturally present obstacles for the use of e-health technology among people diagnosed with schizophrenia. If the users do not own or trust the technology, they will not use it. The users are also described as living outside of society, partly due to this lack of technology use, and therefore may be difficult to reach.

Furthermore, the avoiding coping strategies and lack of illness awareness described in *counteracting improvement behaviour* may not only affect participation in the design process, but also the use of e-health technology. If the users do not consider themselves ill or do not realise that they are ill, then they will not use the technology.

In summary, the wickedness of the design situation in this study has consequences for user involvement in design, and the design, acceptance and use of e-health technology for people diagnosed with schizophrenia. These findings can be useful beyond this study, particularly for the user involvement of and design for people diagnosed with schizophrenia. The literature suggested that there can be different levels of wickedness (Burge and McCall 2015; Farrell and Hooker 2013); the range of complexity and sensitivity of the design situation described here suggests that design of e-health technology for people diagnosed with schizophrenia has a high level of wickedness. Not only is the design situation complex and largely unexplored, but the vulnerability of the users also increases risks and raises ethical considerations for user participation and subsequent use.

This paper shows that grounded theory is a viable approach for understanding wickedness in a design situation. In this case, neither the interrelatedness of the nature of the wicked problems, nor their contradictory nature emerged from the literature. In IS, grounded theory is used to analyse phenomena from a process or situational perspective (Myers 1997; Urquhart 2001). The rigidity of the approach allowed for a systematic

analysis that led to the identification of the contradiction and complexities that cause the wickedness in this design situation. The approach was particularly useful in conceptualising interview data of an explorative nature, and the constant comparison and use of memos to accumulate interpretations made it possible to form an understanding of how the concepts were related.

Furthermore, it was not only considered necessary to ground the study in empirical data from a perspective of understanding, but also from a perspective of ethics. Often people who are considered vulnerable, such as people with mental illness, are excluded from research due to the difficulties of involving them (Liamputtong 2006), yet they may still want to participate despite the challenges (Usher and Holmes 1997) and excluding users can affect the design quality (Bravo 1993). Similarly, both the stakeholders and the people who were diagnosed with schizophrenia who participated in this study expressed that their participation was important to them. The stakeholders further highlighted that there is a great need for anything that can help their children or patients. As a result, when a subject like this is not only rarely studied, but users are often excluded from the research, the ethical value of being grounded in the empirical data is high.

As a final reflection, the grounded approach used in this study was both helpful and led to important insights that have expanded the understanding of the wickedness of designing e-health technology for people diagnosed with schizophrenia. The approach can be useful beyond this study; as the approach is grounded in the perspectives of the participants, and the methods for data collection primarily consists of dialogue, combined with a structured process for analysis focused on identifying relationships, it is transferable to other complex and unexplored design situations. The approach was found particularly supportive of the explorative nature of the study, and would therefore seem particularly suitable in health-related situations where sensitivity is high and situational understanding is paramount.

7   Conclusion

This paper intended to answer the question: *How can the wickedness of the design situation when designing e-health technology for people diagnosed with schizophrenia be understood, and what consequences does the design situation have for the design process?* From a grounded theory analysis of stakeholder interviews and focus group interviews with people diagnosed with schizophrenia, the wickedness is described as consisting of four wicked problems: *struggle of dependence*, *contradiction of social interaction*, *contradiction*

of trust and *counteracting improvement behaviour*. These problems are not mutually exclusive, but together make up the wickedness of the design situation.

The four identified wicked problems have consequences for the involvement of users in design of, and the design, acceptance and use of e-health technology for people diagnosed with schizophrenia. These consequences include the necessity to support expression of technology needs and social interaction, supporting anonymity while at the same time monitoring content quality, and overcoming limited technology use and experience.

In addition to the description of the wickedness of the design situation, this paper also contributes with a viable approach for studying complex and sensitive design situations of this kind. The grounded theory analysis that was used was valuable for capturing, understanding as well as describing the wickedness of the design situation.

Since the design situation is particularly complex, there is a continuous need for research. In order to continue the design of e-health technology for people diagnosed with schizophrenia, it will be important to include users throughout the design process. Nevertheless, more research is also needed on how to involve people diagnosed with schizophrenia in design, and how to begin to tackle the wickedness described here.

Acknowledgment

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