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Wickedness in Design of e-Health Systems for People Diagnosed with Schizophrenia

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Abstract. With the digitisation of society, e-health systems support new contexts that are different from traditional Information Systems contexts, and therefore need to be better understood. In design for complex, new and sensitive contexts, it is not possible to apply known methods and solutions without deeper contextual understanding. The paper intends to answer how the wickedness of the design context when designing digital services for people diagnosed with schizophrenia can be understood – a context that is contradictory and complex, that is, a wicked design context. 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 paper also shows the viability of the use of grounded theory for uncovering and describing contextual 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 contexts and user groups; groups that are heterogeneous, and that use the digital technology in a multitude of contexts [1]. E-health systems are no exception. With the digitalisation of society, e-health systems have to be designed to support user groups who have previously not been supported. Examples include Tokar and Batoroev [2] who explore mobile health care for people with depression, Aardoom, Dingemans and Van Furth [3] who study e-health systems for people with eating disorders and Kowatsch, Maass, Pletikosa Cvijikj, Büchter, Brogle, Dintheer, Wiegand, Durrer-Schutz, Xu and Schutz [4] who study the design of a health information 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 services, it is necessary to understand the context in which they are to be designed and used [5]. It is not possible for one person to have all the necessary knowledge of the complexities of a design context; it therefore becomes imperative to involve stakeholders and support their communication and collaboration [6]. When the design context has been frequently designed for in the past, or is easily relatable, there is little effort in creating an understanding [7].

However, in design for new, complex and sensitive contexts such as health related contexts with vulnerable users, it becomes more difficult to both study and understand the context.

This paper focuses specifically on understanding the context of design of e-health services for people diagnosed with schizophrenia. Approximately 1% of the world's population is diagnosed with schizophrenia [8] and have symptoms such as hallucinations, psychoses, apathy, and cognitive impairment [9]. Symptoms and treatment for schizophrenia can affect the ability for creative thinking [10], clear expression of ideas [11], and social interaction [12]. The treatment for schizophrenia is typically antipsychotic medication, but this has only a limited effect [9].

Designing an e-health system for people diagnosed with schizophrenia means encountering contradictory and sensitive problems that affect the design situation, such as paranoia and delusions [8], and social stigmatisation [13, 14]. These types of problems that are contradictory, incomplete or have constantly changing requirements, have previously been referred to as "wicked problems" [cf. 15]. Design, which is aimed at solving problems, is particularly suitable for handling wicked problems [5, 16]. Understanding a wicked problem is also part in understanding its possible solution, since they are only possible to be understood once they have been solved [15]. This makes understanding the wickedness of a design context critical to the entire design process.

Understanding the wickedness of the context when designing for people diagnosed with schizophrenia is therefore essential but challenging. However, not attempting to gain a complete understanding of the complexities of the design context when it is possible to do so can not only have negative consequences for the quality of the designed system, but can also be considered unethical. Therefore, this paper intends to answer the question: *How can the wickedness of the design context when designing digital services for people diagnosed with schizophrenia be understood?*

Due to the explorative and open nature of the aim, this paper proposes a grounded theory analysis to uncover the wickedness of the context. The purpose is to both describe the wickedness of the context, as well as to discuss the applicability of the grounded theory approach to uncover wickedness in design contexts.

2 Background

2.1 Schizophrenia

Symptoms of schizophrenia can be positive (constituting an addition of abnormal symptoms and behaviours), negative (constituting a lack of normal symptoms and behaviours), or cognitive [8, 9]. These symptoms can be manifested to a different degree among individuals [9]. Positive symptoms can include delusions and hallucinations [9]; in essence a loss of contact with reality [8]. Negative symptoms include flat affect, social withdrawal and reduced speech [8, 9]. These symptoms are less fluctuating than the positive symptoms and also have a greater effect on the person's social life [8]. Many also have cognitive impairments, such as problems with

attention, learning and memory, illogical thinking, confusion, delusion and strange linking of thoughts [8, 11, 17].

There is no cure for schizophrenia, only ways to cope with the illness. Most recover after the first onset, but about 10% never do [9]. The outcome seems more promising in developing countries than in developed countries [9]. The primary treatment in developed countries is antipsychotic medication that primarily treats positive symptoms [9]. Antipsychotic medication does not appear to improve cognitive function, and even though other symptoms improve, these cognitive symptoms tend to remain [17]. Psychosocial treatment such as supported employment and social skills training has been found to improve the outcome of schizophrenia [8].

The social and emotional limitations that people diagnosed with psychotic disorders, such as schizophrenia, experience can often lead to isolation [18]. Social support has been found to have several benefits for people diagnosed with schizophrenia and similar severe mental illnesses [19-22]. 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 [18]. Increasingly, people diagnosed with schizophrenia are turning to social media not specifically designed for their needs for support, risking low quality support and being identified as an individual with such an illness and its associated stigmatisation [23]. People diagnosed with mental health conditions in younger generations are also more likely to use social media to build friendships [24].

2.2 Wicked Problems

The concept of wicked problems was initially described by Rittel and Webber [15]. 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 [15]. Social problems [15] and the problems approached using non-linear design processes are usually of a wicked nature [25]. In fact, all problems except those taken on by routine design are wicked problems [5]. There is no single right or wrong solution [26]; the solution of a wicked problems lies in the world view of the solver [15], in this case the designer [27].

In the attempt to solve wicked problems, all actions taken will affect the surrounding context and there is thus no way to undo mistakes [15]. Therefore, it becomes important to reduce the possibility for mistakes. Yet there are no categories of wicked problems, nor are there any predefined ways of solving them; all wicked problems are unique [15]. Wicked problems 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 [26]. The common collaboration between different people in design is suitable for tackling wicked problems [28].

The aim for this paper is to begin the process of understanding, and thus enable handling of, some of the wicked problems that exist in the design context when designing digital services for people diagnosed with schizophrenia. 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 context in which the problem resides [26]. Instead of oversimplifying, it is important to consider the problem on different levels, systemically [26]. Familiarizing oneself with the context is also an important step in better utilizing the empirical material to create theories [29], and there are calls for more systemic ways of expressing and using context in theory development [30]. This paper is a step towards creating a deeper contextual understanding of the wickedness of design of e-health systems for people diagnosed with schizophrenia.

3 Method

This paper employs a grounded theory analysis to answer how the wicked problems in the design of e-health systems for people diagnosed with schizophrenia can be understood. 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 contexts and settings under study [31]. Grounded theory was first introduced by Glaser and Strauss [32] and has since developed in different directions. This paper relies on the work of Charmaz [31] as a foundation for the methodology employed. Charmaz [31] 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 can be in the early stages of a design process, in order to gain a systematic and deep understanding of the context and problem area [33].

It is becoming increasingly popular to use grounded theory in the Information Systems (IS) field, as it is considered useful for describing processes and phenomena [34]. However, the existence of some myths about the nature of grounded theory has been considered the cause of misuse or lack of use of grounded theory in the field [35]. These myths include for example the misconception that literature cannot be studied before performing a grounded theory analysis [35, 36]. Instead, literature should be studied beforehand, but not in order to integrate into the yet unidentified theory [35]; it should be used strategically [31]. 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 complex and contradictory situations within the studied context, and these were identified to be wicked problems. The literature on wicked problems was then incorporated.

3.1 Study Design

The empirical material included in this study consisted of: semi-structured stakeholder interviews, four with relatives of people diagnosed with schizophrenia and three with medical professionals; and two focus group interviews, each with two people diagnosed with schizophrenia. The focus group interviews were part of the first of three design workshops with the aim to design an e-health system. 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. The open codes were then grouped into categories using focused coding. The core to grounded theory is considered to be constant comparison between data, codes and categories [31]. 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 or the most frequent codes as a starting point. Examples of categories identified at this stage include *depending on others*, *having illness awareness*, and *using strategies*.

The relationships between the identified categories were then axially coded. This was done using 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 this stage that the wicked problems were identified in the conflicting nature of the categories. Theoretical coding was then done, but those results will not be possible to include in this paper. Memos were also written throughout the analysis process, as recommended by Charmaz [31]. These were important for recording insights and interpretations throughout the analysis.

The results presented in this paper are 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. The results from the grounded theory analysis thus related to more than the wicked problems described in this paper.

3.2 Research Context

The research in this paper was performed within a research project aimed to design an e-health system for people diagnosed with schizophrenia. E-health systems have been designed for similar contexts. For example, Melling and Houguet-Pincham [37] study an e-health system for people who are experiencing depression, Webb, Burns and Collin [38] develop an e-health system for adolescents who are experiencing mental health difficulties, and Lederman, Wadley, Gleeson and Alvarez-Jimenez [39] design online social therapy meant to detect warning signs among young people with psychoses. Each of these cases illustrates the complexity of the context, and the necessity to understand the context as part of the design process, in order to adapt both the design process and the final e-health system. The data collected here is part of an early part of the project. The following part of the project included design workshops together with people diagnosed with schizophrenia with the aim to collaborate in design.

3.3 Participants

The participating stakeholders were four parents of people diagnosed with schizophrenia, one activity coordinator, one psychiatric nurse, and one assistant nurse working with housing support. The participating target 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 1 below gives an overview of the participants and their roles.

Table 1. Overview of participants.

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
Target user	Frank Scott David Angela

3.4 Ethics

The regional ethical review board approved the project (Dnr 2011/267) from which the collected empirical material in this paper comes. When the context is sensitive, as in this paper, there is a risk to the participants' welfare. 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 stigmatization of mental health illnesses such as schizophrenia [14]. During the interviews, the relatives of people with schizophrenia expressed concern that if their participation became known, it would negatively affect their children. As a result, 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 of experience working with 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.

4 Findings

This section presents the results from the analysis of how the wicked problems in the design of e-health systems for people diagnosed with schizophrenia can be understood. Table 2 below summarizes the uncovered wicked problems that are described in detail in this section.

Table 2. Summary of the identified wicked problems.

Contextual 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 of the increasingly digitized society, deepening their dependence.
Contradiction of social interaction	People diagnosed with schizophrenia lose most social connections yet acquire many medical contacts. This, along with stigmatization, makes interaction impersonal and people are often lonely. Medical contacts enhance social behavior that serves to alienate others.
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 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 behavior	Some behavior directly counteracts possibilities for improvement. People diagnosed with schizophrenia tend to use avoiding coping strategies and isolating behaviors, increasing their loneliness. Balance tends to disappear.

4.1 The 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 like:

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 as a 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 on others to be activated. Dani's and Jack's mothers, psychiatric nurse Benjamin, and 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, 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 most 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 to learn 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.

There is 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 issues described will no longer be valid. However, it will still be many years when these issues stay relevant.

4.2 The 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 Christ says that social life becomes 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 the 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.

4.3 The Contradiction of Trust

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

4.4 The 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 8 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 ability to cope and 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. 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.

5 Discussion

This paper has uncovered wickedness of the design context when designing digital services for people diagnosed with schizophrenia. Four wicked problems in the design context have been identified. Hereby, this paper demonstrates the viability of a grounded approach to uncover wickedness of design contexts with the intent to gain contextual awareness in complex and sensitive design contexts. In this section, the uncovered wickedness will be discussed along with the approach to uncover them.

The contextual 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 services for people diagnosed with schizophrenia. As Buchanan [27] explains, wicked problems stem from the nature of the design subject; wicked problems are wicked because design implies discovery.

The wicked problems uncovered in this study are interrelated, and not mutually exclusive. As any wicked problems, they are indefinable, untestable, and unique to the context [15]. For example, the *struggle of dependence* and the *contradiction of trust* are related in that dependence causes a need to trust. If people diagnosed with schizophrenia had not been dependent on others, they would not be contradictorily trusting. However, it is equally possible that if the contradiction of trust had not existed, there would not be a struggle of dependence. As such, the wickedness of this context is not a single problem, but a chain of interrelated complexities that together make up the wickedness of the design context.

In this case, any designed artefact or outcome of a design process would have to deal with the contextual wickedness. Goldkuhl [40] argues that one part of a design theory is empirical grounding, which should answer whether the outcome is successful in practice and if it leads to its desired consequences. To answer this, we need to understand what would make an outcome successful, and its desired consequences; the first step in understanding this is to empirically study the context.

This paper shows that grounded theory is a viable approach for gaining understanding of wickedness in a design context. 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 context perspective [36, 41]. The rigidity of the method allowed for a structured analysis that led to uncovering the contradiction and complexities that cause the wickedness in this design context.

Furthermore, it was not only considered necessary to ground the study of the design context in empirical data from a theory-creating perspective, but also from an ethical perspective. Often people who are considered vulnerable, such as people with mental illness, are excluded from research due to the difficulties of involving them [42], yet they may still want to participate despite the challenges [43]. 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 in IS research, 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 the uncovering of many important insights that have expanded the understanding of the design context when designing digital services for people diagnosed with schizophrenia. The approach can be useful in contexts beyond this study; as the approach is grounded in the perspectives of the participants, and the methods for data collection primarily consists of dialogue, it is transferable to other complex and unexplored design contexts. It would seem particularly suitable in health-related contexts where sensitivity is high and contextual understanding is paramount.

The understanding of wickedness in design contexts that has been gained from this study can be used to support both the design process and design of e-health systems. For example, the *contradiction of trust* and the *contradiction of social interaction* indicate that the e-health service would need to enforce healthy social interaction and moderating the quality of the information, while at the same time creating the ability for the users to trust both the system and the other users. User participation in the design process is made more difficult by the *struggle of dependence* and the *contradiction of social interaction*, as users would have to both express their opinions and participate in the social process of designing with others.

6 Conclusion

This paper intended to answer the question: *how can the wickedness of the design context when designing digital services for people diagnosed with schizophrenia be understood?* From a grounded theory analysis of stakeholder interviews and focus group interviews with people diagnosed with schizophrenia the contexts is described as consisting of four wicked problems: the struggle of dependence, the contradiction of social interaction, the contradiction of trust and the counteracting improvement behaviour. These problems are not mutually exclusive, but together make up the complexity of the design context.

In addition to the description of the wickedness of the design context, this paper also contributes with a viable approach for studying complex design contexts of this kind. The grounded theory analysis that was used was valuable for capturing and describing the complexities of the context.

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

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References

1. Iivari, J., Isomäki, H., Pekkola, S.: The user—the great unknown of systems development: reasons, forms, challenges, experiences and intellectual contributions of user involvement. *Information systems journal* 20, 109-117 (2010)
2. Tokar, O., Batoroev, K.: Identifying Opportunities for Future Design Research for mHealth for Mental Health. In: *Proceedings of ECIS 2016*, pp. Paper 65. (2016)

3. Aardoom, J.J., Dingemans, A.E., Van Furth, E.F.: E-Health Interventions for Eating Disorders: Emerging Findings, Issues, and Opportunities. *Current psychiatry reports* 18, 1-8 (2016)
4. Kowatsch, T., Maass, W., Pletikosa Cvijikj, I., Büchter, D., Brogle, B., Dintheer, A., Wiegand, D., Durrer-Schutz, D., Xu, R., Schutz, Y.: Design of a Health Information System Enhancing the Performance of Obesity Expert and Children Teams. In: *Proceedings of ECIS 2014*. (2014)
5. Hevner, A.R., March, S.T., Park, J., Ram, S.: Design science in information systems research. *MISQ* 28, 75-105 (2004)
6. Arias, E., Eden, H., Fischer, G., Gorman, A., Scharff, E.: Transcending the individual human mind—creating shared understanding through collaborative design. *ACM Transactions on Computer-Human Interaction (TOCHI)* 7, 84-113 (2000)
7. Gregor, S., Hevner, A.R.: Positioning and presenting design science research for maximum impact. *MISQ* 37, 337-356 (2013)
8. Mueser, K.T., McGurk, S.R.: Schizophrenia. *The Lancet* 363, 2063-2072 (2004)
9. Frangou, S.: Schizophrenia. *Medicine* 36, 405-409 (2008)
10. Andreasen, N.C.: Schizophrenia: the fundamental questions. *Brain Research Reviews* 31, 106-112 (2000)
11. Schuldborg, D.: Six subclinical spectrum traits in normal creativity. *Creativity Research Journal* 13, 5-16 (2001)
12. Couture, S.M., Penn, D.L., Roberts, D.L.: The functional significance of social cognition in schizophrenia: a review. *Schizophrenia bulletin* 32, S44-S63 (2006)
13. Davidson, L., Shahar, G., Stayner, D.A., Chinman, M.J., Rakfeldt, J., Tebes, J.K.: Supported socialization for people with psychiatric disabilities: Lessons from a randomized controlled trial. *Journal of Community Psychology* 32, 453-477 (2004)
14. Campellone, T.R., Caponigro, J.M., Kring, A.M.: The power to resist: The relationship between power, stigma, and negative symptoms in schizophrenia. *Psychiatry research* 215, 280-285 (2014)
15. Rittel, H.W., Webber, M.M.: Dilemmas in a general theory of planning. *Policy sciences* 4, 155-169 (1973)
16. Zimmerman, J., Forlizzi, J., Evenson, S.: Research through design as a method for interaction design research in HCI. In: *Proceedings of CHI*, pp. 493-502. ACM, (2007)
17. Wilder-Willis, K.E., Shear, P.K., Steffen, J.J., Borkin, J.: The relationship between cognitive dysfunction and coping abilities in schizophrenia. *Schizophrenia Research* 55, 259-267 (2002)
18. Castelein, S., Bruggeman, R., Davidson, L., van der Gaag, M.: Creating a supportive environment: Peer support groups for psychotic disorders. *Schizophrenia bulletin* 41, 1211-1213 (2015)
19. Davidson, L., Chinman, M., Kloos, B., Weingarten, R., Stayner, D., Tebes, J.K.: Peer support among individuals with severe mental illness: A review of the evidence. *Clinical psychology: Science and practice* 6, 165-187 (1999)
20. Lloyd-Evans, B., Mayo-Wilson, E., Harrison, B., Istead, H., Brown, E., Pilling, S., Johnson, S., Kendall, T.: A systematic review and meta-analysis of randomised controlled trials of peer support for people with severe mental illness. *BMC psychiatry* 14, 1 (2014)
21. Castelein, S., Bruggeman, R., Van Busschbach, J.T., Van Der Gaag, M., Stant, A., Kneegting, H., Wiersma, D.: The effectiveness of peer support groups in psychosis: a randomized controlled trial. *Acta Psychiatrica Scandinavica* 118, 64-72 (2008)
22. Chinman, M., George, P., Dougherty, R.H., Daniels, A.S., Ghose, S.S., Swift, A., Delphin-Rittmon, M.E.: Peer support services for individuals with serious mental illnesses: assessing the evidence. *Psychiatric Services* 65, 429-441 (2014)

- 23.Naslund, J.A., Grande, S.W., Aschbrenner, K.A., Elwyn, G.: Naturally occurring peer support through social media: the experiences of individuals with severe mental illness using YouTube. *PloS one* 9, e110171 (2014)
- 24.Gowen, K., Deschaine, M., Gruttadara, D., Markey, D.: Young adults with mental health conditions and social networking websites: Seeking tools to build community. *Psychiatr Rehabil J* 35, 245 (2012)
- 25.Farrell, R., Hooker, C.: Design, science and wicked problems. *Design Studies* 34, 681-705 (2013)
- 26.Nelson, H.G., Stolterman, E.: The design way: Intentional change in an unpredictable world: Foundations and fundamentals of design competence. *Educational Technology* (2003)
- 27.Buchanan, R.: Wicked problems in design thinking. *Design issues* 8, 5-21 (1992)
- 28.Hawryszkiewicz, I.: Visualizations for Addressing Wicked Problems Using Design Thinking. In: *Proceedings of European Conference on Information Systems 2014*. (2014)
- 29.Alvesson, M., Kärreman, D.: Constructing mystery: Empirical matters in theory development. *Academy of management review* 32, 1265-1281 (2007)
- 30.Hong, W., Chan, F.K., Thong, J.Y., Chasalow, L.C., Dhillon, G.: A framework and guidelines for context-specific theorizing in information systems research. *Information Systems Research* 25, 111-136 (2013)
- 31.Charmaz, K.: *Constructing grounded theory: A practical guide through qualitative research*. SagePublications Ltd, London (2006)
- 32.Glaser, B.G., Strauss, A.L.: *Discovery of grounded theory*. Sociology Press, Mill Valley, CA (1967)
- 33.Gregory, R.: Design Science Research and the Grounded Theory Method: Characteristics, Differences, and Complementary Uses. In: *Proceedings of ECIS 2010*, pp. Paper 44. (2010)
- 34.Hughes, J., Jones, S.: Reflections on the use of grounded theory in interpretive information systems research. *Proceedings of ECIS 2003*, pp. Paper 62 (2003)
- 35.Urquhart, C., Fernandez, W.: Grounded theory method: the researcher as blank slate and other myths. In: *Proceedings of ICIS 2006*, pp. Paper 31. (2006)
- 36.Urquhart, C.: An encounter with grounded theory: tackling the practical and philosophical issues. *Qualitative research in IS: Issues and trends* 104-140 (2000)
- 37.Melling, B., Houguet-Pincham, T.: Online peer support for individuals with depression: A summary of current research and future considerations. *Psychiatr Rehabil J* 34, 252 (2011)
- 38.Webb, M., Burns, J., Collin, P.: Providing online support for young people with mental health difficulties: challenges and opportunities explored. *Early Interv Psychiatry* 2, 108-113 (2008)
- 39.Lederman, R., Wadley, G., Gleeson, J., Alvarez-Jimenez, M.: Using On-Line Technologies To Identify And Track Early Warning Signs Of Psychosis. In: *Proceedings of the 21st European Conference on Information Systems - Research in Progress*, pp. Paper 1. (2013)
- 40.Goldkuhl, G.: Design theories in information systems-a need for multi-grounding. *JITTA: Journal of Information Technology Theory and Application* 6, 59 (2004)
- 41.Myers, M.D.: Qualitative research in information systems. *Management Information Systems Quarterly* 21, 241-242 (1997)
- 42.Liamputtong, P.: *Researching the vulnerable: A guide to sensitive research methods*. Sage, London (2006)
- 43.Usher, K., Holmes, C.: Ethical aspects of phenomenological research with mentally ill people. *Nursing Ethics* 4, 49-56 (1997)