Looking at the world through a frosted window: experiences of loneliness among persons with mental ill-health

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Accessible summary
- Experiences of loneliness among people with mental ill-health can be metaphorically described as looking at the world through a frosted window.
- The experiences are multifaceted and developing as well as emotionally and socially excluding.
- People suffering from mental ill-health and loneliness carry a twofolded stigma. They feel socially undesirable, and the social perceptions of lonely people are generally unfavourable.

Abstract
Mental ill-health is reported to be of major concern in public health. Persons suffering from mental ill-health are a vulnerable group, and loneliness influences the perception of physical, social, and emotional well-being. However, there are few studies exploring lived experiences of loneliness among people with mental ill-health. This qualitative study aimed to illuminate experiences of loneliness among people with mental ill-health. Five individual, informal conversational interviews were performed and subjected to qualitative content analysis. The main findings showed that experiences of loneliness could be metaphorically described as looking at the world through a frosted window. The experiences of loneliness were multifaceted and altering as well as emotionally and socially excluding. The findings are discussed in relation to Tillich dimensions of loneliness: loneliness as a painful dimension of being alone, and solitude as the enriching dimension of being alone. People suffering from mental ill-health carry a twofolded stigma. They feel socially undesirable because of their mental ill-health, and the social perceptions of lonely people are generally unfavourable. We believe that mental health nurses can support the developing and creative dimension of loneliness through a confirming approach, where people with mental ill-health feel seen, heard, and respected as human beings.

Introduction
Loneliness is considered to be a multidimensional phenomenon (de Jong Giervald 1998, Nilsson et al. 2006); it is a personal and subjective experience related to the individual’s gender, age, marital status, and social relations, as well as to the aspects of the cultural and religious context. Of significance are the individual’s values, self-image, desires, and needs, as well as personal opinions about social relations and the phenomenon of loneliness (Wiseman et al. 2005, Cacioppo et al. 2006, Mellor et al. 2008, Civitci & Civitci 2009, de Jong-Giervald et al. 2009).

There is no clear consensual definition of loneliness (Karnick 2005). The concepts of feeling lonely, being alone, and living alone are often used interchangeably; although they are distinct concepts (Routasalo & Pitkala 2003), they
are related and constitute dimensions of loneliness. In this paper, we refrain from defining loneliness, as our main focus was to illuminate the experiences of loneliness as described by persons with mental ill-health.

People experience and describe loneliness in multiple ways. Thesen (2001) described loneliness as a continual, painful companion that causes people to regard their affliction as a personal defect or deficiency. Dahlberg (2007) reported on loneliness from a life-world perspective among women and men aged between 12 and 82 years. She described the essence of loneliness as loneliness without others; loneliness with others; loneliness as a strange, wrong, ugly, or even shameful thing; and loneliness as a restful and creative thing. Eshbaugh (2008) described negative, neutral, and positive experiences of loneliness among older adult women living alone. Their utterances concerning their experiences of loneliness varied between I hate it, I’m used to it now and I love it. According to Graneheim & Lundman (2010), the experiences of loneliness among the very old were twofold; on the one hand, living with losses and feeling abandoned represented the limitations imposed by loneliness; and on the other hand, living in confidence and feeling free represented the opportunities of loneliness.

Mental ill-health is reported to be of major concern in public health. Persons suffering from mental ill-health are a vulnerable group, and loneliness influences the perception of physical, social, and emotional well-being (Nilsson et al. 2008). Loneliness is significantly associated with mental ill-health (Syren 2010), especially depression (Victor & Yang 2012), and living with mental ill-health influences physical and psychological prerequisites to creating social networks and close relations. Thus, mental ill-health can contribute to experiences of being unwanted, unimportant, stigmatized, and lonely (Erdner et al. 2005). People with mental ill-health reported a sense of loneliness, from having no friends and experiencing a huge vacuum, to having contact with family and friends, but still experiencing loneliness (Granerud & Severinsson 2006).

In summary, people with mental ill-health are stigmatized (Erdner et al. 2005), and their experiences are seldom addressed, and if so, their experiences are often neglected and referred to their mental ill-health (Lindgren et al. 2004). Even though it is evident that experiences of loneliness influence mental ill-health, there are few studies concerning these experiences among persons with mental ill-health. Today, a large number of people suffering from mental ill-health are cared for in their own homes and offered support by the community. In order to open up a dialogue about loneliness in this context, it is important to know how they experience their situation and loneliness as a part of their lives.

Aim

This study aimed to illuminate the experiences of loneliness as described by people with mental ill-health.

Methods

This is a qualitative study based on individual, informal conversational interviews, using qualitative content analysis, to derive the experiences of loneliness among people with mental ill-health. The epistemology of qualitative content analysis has been considered unclear (Lundman & Graneheim 2012). However, we argue that qualitative content analysis comprises phenomenological descriptions of the manifest concrete content, close to the text, as well as hermeneutic interpretations of the latent abstracted message, yet still close to the subjects’ experiences. Thus, different stages in the analysis process can be referred to various scientific approaches (Schreier 2012). In this study, we both described the manifest content and interpreted the latent message.

Context

In order to facilitate recovery and rehabilitation for people with mental ill-health, the community offer various kinds of support, for example, support at home, special housing, and assistance finding something meaningful to do. Within the area of personal support, the community offers help concerning daily living, relations, finances, and contacts with authorities. Concerning employment, meaningful activities, and studies, there are adapted and structured workplaces and work-oriented rehabilitation, with access to individual supervision (counselling) as well as opportunities to study with special pedagogical support. There are also social meeting centres and opportunities to participate in cultural activities. The study was performed among persons visiting two social meeting centres in a midsized city in northern Sweden. These houses are part of a social cooperative run by the users and next-of-kin organizations. The cooperative is mainly a social meeting centre, open every day during the year, where influence and participation are key concepts. Besides the opportunity to ‘just be’, they offer activities such as playing music, watching movies, painting, working with computers, and making pottery.

Participants

For our study, we contacted the managers at two social meeting centres for people with mental ill-health and got permission to arrange an information meeting. The second
and third (ME) authors provided information about the project, and those attendees who were willing to participate could signify their interest. The inclusion criteria were having lived experiences of mental ill-health, not being admitted to inpatient care, visiting the social meeting centres on a regular basis, and being willing to share their experiences verbally. Eight persons were interested in participating. However, three of them were not able to fulfil their participation because of personal reasons. The five remaining participants were three men and two women, between 25 and 57 years of age. Self-reported diagnoses were, for example, depression, anxiety, and psychosis. Their length of experience of living with mental ill-health ranged between 7 and 30 years. Three participants were cohabiting, and two had children.

Informal conversational interviews

Aiming to illuminate the experiences of loneliness, the second and the third authors performed informal conversational interviews, during November 2009 and February 2010, with five persons who met the inclusion criteria. An informal conversational interview has an open-ended approach and is both unstructured and focused (Patton 2002, pp. 342–343). The focus of the current interviews was on the participants’ experiences of loneliness, with examples of questions asked being, ‘Could you please tell me about your experiences of loneliness?’ The responses were followed up with clarifying and exploratory questions, such as ‘How do you mean? Can you tell us more about that?’ Whenever the interviewees did not spontaneously reflect on their descriptions, their reflections were solicited. The interviewees told about their experiences of loneliness throughout life.

The informal conversational interviews were performed at the social meeting centres, except for one that took place in the participant’s home. The tape-recorded interviews lasted between 30 and 90 min (median = 45 min) and were transcribed verbatim.

Analysis

The transcribed text was subjected to qualitative content analysis (Graneheim & Lundman 2004). Content analysis systematically analyses written or verbal communication (Krippendorff 2004), focusing on differences between, and similarities within, parts of the text, and the interpretation process results in categories and/or themes (Graneheim & Lundman 2004).

The analysis was performed in several steps. First, the text was read several times to get a sense of the whole. Then the text was divided into meaning units, for example, words, sentences, and paragraphs related to each other through their content and context. The meaning units were condensed, while still preserving their core meaning, and labelled with a code. Codes that deviated from the aim were excluded, for example, comments on the weather, actual television programmes, and other visitors to the centre. The remaining codes were sorted into four subcategories, and eventually abstracted to two categories at a manifest level. Finally, the categories were reflected on, and a theme, that is, a thread of latent meaning running through codes on an interpretative level, was formulated (Graneheim & Lundman 2004).

To enhance trustworthiness, the codes, subcategories, categories, and theme were reflected on and discussed in the research team throughout the analysis process, resulting in consolidation of the findings.

Ethical considerations

This study was accomplished according to the ethical guideline described in the Helsinki Declaration (World Medical Association 2008). Furthermore, the study was approved by the managers at the social meeting centres. Participants received verbal and written information about the aim of the study, and they decided on their own whether they wanted to participate. Nonetheless, there were risks that need to be taken into consideration. Participants can feel violated by close questioning. However, the participants in our study could choose what they wanted to tell and were informed that they could end their participation whenever they wished. They were also assured of confidentiality. Furthermore, expressing their experiences may provide relief for the participants (Gaydos 2005).

Findings

The participants experienced loneliness as multifaceted and altering, and as emotionally and socially excluding, which was interpreted as an experience of looking upon the world through a frosted window.

Looking upon the world through a frosted window

The picture that emerged from the participants’ descriptions about experiences of loneliness could be understood as being on one side of a frosted window. Through this window, covered in crystals of ice, the persons with mental ill-health viewed people in the surrounding world and their solidarity, and this reminded them of their loneliness. Whether participants perceived themselves to be on the inside looking out or on the outside looking in, the contours of the surroundings, fellow beings, and phenomena
were shattered, looked somewhat diffuse, were hard to understand and achieve, but were yet considered something worth striving to be a part of. The ice crystals made the light reflect in various ways that symbolized the multifaceted and altering experiences of loneliness. Furthermore, the frosted window became a symbol for emotional and social exclusion, from the world and society, as shared through the participants’ descriptions. Thus, the experience of one’s own existence, the world in relation to others, and one’s social context, could change and alter the experience of loneliness. Because of shifting seasons, the frost could melt away, and if the conditions were right, loneliness could be experienced as developing. However, the window was still there as a reminder of being included and hindered from participating in social life. Categories that constitute the theme are presented later and illuminated by quotations.

**Multifaceted and altering**

The experiences of loneliness were multifaceted and altering, described as *varying with situation in life and endless*, but also as *a developing experience*.

The multifaceted nature of loneliness reflected the participants’ life situation, health status, memories from the past, and expectations and worries for the future. One of the participants described how emotional difficulties such as anxiety could drain energy and stamina, resulting in an inability to maintain social relationships, in the long run leading to loneliness. She stated, ‘Anxiety and other stuff hindered, and sort of kept me from . . . I just did not have the energy to maintain social relationships and that, of course, creates loneliness’ (P3).

The experiences of loneliness shifted over the course of time. The participants described that the experiences of loneliness varied throughout life and were related to the individual social situation, such as the quality of relationships and whether the person had the ability, will, and opportunity to express the emotions that loneliness brings. One man said, ‘Apparently there are a lot of different ways; it depends on where you are in life, your relationships, and if you have the ability to talk about it’ (P1).

Varying with life situations, loneliness could be involuntary as well as voluntary. The participants expressed that involuntary loneliness could be a necessity, when it became difficult to handle social relationships in everyday life. However, even though loneliness was not by choice, it could be experienced as beneficial. One woman reported, ‘I could not cope with having to work alongside others . . . so I chose to work by myself most of the time’ (P2). Involuntary loneliness was also described as an experience that almost everyone, at some point in life, had experienced, especially when relationships with others failed, changed, or was ended. The same woman said, ‘If your relationship fails, loneliness will be present and there is nothing strange about that’ (P2).

Sometimes, the experience of loneliness was continuously present and endless, and created a sense of emptiness and hopelessness, and of life being meaningless. The experiences of loneliness became a vicious circle, and ongoing phenomena in life that never seemed to end. As one woman told, ‘I could wake up and there was no end to it . . . I just thought that the only thing of worth today was to pull up the blinds’ (P2). The participants described loneliness as latent and a constant reminder of how life can be, even when loneliness no longer was present. A man said, ‘But it’s kind of still present and guides you in life . . . because you kind of put it behind you, but yet the feeling is present . . . It’s latent . . . so that you won’t forget’ (P5). This contributed to the experiences of loneliness as an inevitable part of, or as a lot in, life. One woman told, ‘. . . I thought it was what I’ve been given in life, my lot in life . . . ’ (P2).

The experiences of loneliness were also described as voluntarily chosen and developing, meaning that loneliness could be a relief from the hardships of social interaction and sometimes a necessity. The participants described that loneliness could be beneficial, existentially rewarding, and a driving force in life, because the experiences of loneliness will create a reference to the experience itself, from which desires and striving for future social situations could be shaped. One man said, ‘Well, you need time for yourself too . . . but that is a positive loneliness. You can be by yourself without it being negative. Before, I did not see it like that . . . that loneliness can be beneficial’ (P5).

**Emotionally and socially excluding**

The experiences of loneliness, as shared by the participants, could bring a sense of emotional and social exclusion, described as *lack of belonging and feeling set aside*. Lack of belonging fostered feelings of being insignificant and inadequate. The participants related that when they and their emotions were unimportant to their close family, it created a fundamental feeling of exclusion. Furthermore, lack of belonging was intensified when there was an inability to return to, maintain, and/or create social networks. As one man said, ‘It’s not easy to rebuild your social network or friendships when you don’t have the ability to’ (P4).

Feeling set aside included feelings of not being acknowledged, that is, not being heard, seen, or understood by others. This could be due to a physical lack of someone to open one’s heart to, as well as lack of feeling understood on an emotional level and not being allowed to express emotions or experiences.
The lack of belonging as well as feeling set aside influenced the experiences of loneliness and affected the perceived self-confidence and self-image, which created ambivalence, confusion, and insecurity, when it came to self-worth and individual importance. One woman said, ‘Not having relationships or someone that reflects who you are as a person... well, someone to validate you and your actions... you will feel that you’re not of importance as a person’ (P3).

Discussion

The aim of this study was to illuminate the experiences of loneliness among people with mental ill-health. The findings showed that the experiences of loneliness were multifaceted and altering as well as emotionally and socially excluding. The latent meaning of these categories formed the theme looking upon the world through a frosted window.

Tillich (1963) suggests using two words for the multifaceted experience of loneliness, loneliness to express the painful dimension of being alone and solitude to express the developing dimension of being alone.

Similar to Tillich’s (1963) dimension of solitude as the glory of being alone, we found that the experience of loneliness could be enriching, a driving force towards togetherness and belonging of a larger social context. Experiences of loneliness were considered as a source of wisdom and personal growth. Tillich described that solitude can be found in music, literature, and art, and he stated that ‘one hour in conscious solitude does more for your creativity than many hours of learning how to become creative’ (p 553). This is echoed in Dahlberg (2007), who described voluntary loneliness to be a powerful and creative experience, which offered inner peace and calm. Furthermore, Graneheim & Lundman (2010) described the opportunities offered by loneliness among the very old as living in confidence and feeling free.

There is a strong relation between loneliness and perceived physical and mental health status over time. The relation is two-sided: a decrease in experience of loneliness increases perceived physical and mental health at the same time as a deterioration of physical and mental health increases the experience of loneliness (Nummela et al. 2011). Our study shows that even though the experience of loneliness varies throughout life and by the influence of a number of factors, such as phase of life, social situation, and the presence of friends, the experience of loneliness still is continuously present. In a literature review on existential loneliness Ettema et al. (2010), the authors found three dimensions of existential loneliness, as a basic condition of human existence, as a specific experience, and as a process in which the negative experience of a man’s lonely nature is transformed into a positive one. Tillich (1963) advocated that human beings have always suffered from experiences of loneliness and thereby had a wish to escape this loneliness. With other words, lonely is not something you become; it is something you are, which echoes our findings that experiences of loneliness are continuously present.

The experience of loneliness was described as not belonging and being set aside. It was a social and emotional exclusion that throughout life fostered feelings of hopelessness and was perceived as endless. Unfulfilled wishes and expectations of life and social relations contributed to disappointment and pain. This is supported by Peplau & Perlman (1982), who reported that loneliness occurs when individuals perceive a difference between their desired and actual levels of social involvement. Furthermore, we found that feeling set aside, including not being heard, seen, or understood, fostered experiences of loneliness even when being surrounded by people. These feelings of exclusion contributed to resignation, frustration, and desperation. According to Tillich (1963), the experience loneliness and isolation could be present among family members, neighbours, co-workers, and friends. This contributes to a need to retire from the group in order to be alone with the loneliness. Buber (1957, 1994) suggests that you become someone in relation to others, and a person’s identity is promoted by confirmation. Feeling emotionally and socially excluded can derive from experiences of disconfirmation. According to Cissna & Seaburg (1981), disconfirmation means ‘To me, you do not exist’, ‘We are not relating’, ‘To me, you are not significant’, and ‘Your way of experiencing your world is invalid’. The participants in our study expressed this by saying that they and their emotions were insignificant to their close relatives, and there was no one around who could validate them and their actions.

People suffering from mental ill-health are stigmatized (Erdner et al. 2005). Furthermore, loneliness carries a significant social stigma, as lack of friendship and social ties is socially undesirable, and the social perceptions of lonely people are generally unfavourable (Rokach 2012). Knight et al. (2003) describe social exclusion as not only a consequence of mental ill-health but also an experience of stigmatization. The ideological foundation of the development from institutionalized to decentralized psychiatry was social integration (National Board on Health and Welfare 1992). Modern community health-care views social integration as vital for improving mental health (Granerud & Severinsson 2006). However, without active interventions in the form of community participation and individual support, people with mental ill-health who move into private housing can find themselves excluded from the social network (Hardiman & Segal 2003).
Methodological discussion

The number of participants in this study is small. However, the interviews conducted resulted in a large amount of material, illuminating differences and similarities in the participants’ experiences of loneliness. Thus, five participants were assessed to be enough, as trustworthiness in a qualitative study is gained more by the richness of each interview than by sample size (Sandelowski 1995).

Conducting informal conversational interviews, with two authors present, can be considered as both a weakness and a strength. On the one hand, it can create an unnatural and inhibiting atmosphere for all involved because the participants are sharing private and intimate thoughts and experiences, which are sometimes very emotional. It could be argued that an already unfamiliar situation for the interviewees could be even more exposing with a three-way conversation. On the other hand, the presence of both authors created a setting for a more active conversation concerning the participants’ experiences of loneliness and thus a greater variation in data.

Some of the results and quotations of this study may reflect not only the experiences of loneliness, but also the experiences of suffering from mental ill-health. One reason for this may be the complex nature of human experiences. It is not always possible to separate intertwined feelings from each other, that is, experiences of loneliness and living with mental ill-health cannot always be isolated from each other.

Our interpretation should be considered as one possible understanding of the experiences of loneliness among people with mental ill-health. According to Krippendorff (2004), a text never implies one single meaning, just the most probable meaning from a particular perspective. In order to enhance trustworthiness, the authors discussed every step in the analysis process, until consensus about the interpretation was achieved. We also reflected on our findings in relation to the text and relevant literature.

Conclusions and relevance for practice

Our study showed that experiences of loneliness among people with mental ill-health can be metaphorically described as looking at the world through a frosted window. Furthermore, people suffering from mental ill-health and loneliness carry a twofolded stigma. They feel socially undesirable because of their mental ill-health, and the social perceptions of lonely people are generally unfavourable. Loneliness was described as an inevitable part of, or as a lot, in life. This is in accordance with Tillich (1963) who argues that the fundamental issues of loneliness is the fact that being alive means being in a body, separated from all other bodies, and being separated means being alone. By addressing these issues, we believe that mental health nurses can reduce the experiences of loneliness and support the developing and creative dimension of loneliness that is, solitude. This can be achieved through a confirming person-centred approach, where people with mental ill-health feel seen, heard, and respected as human beings. Furthermore, by encouraging solitude, people with mental ill-health may come to peace with loneliness.

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References


