Uncertainty in illness among people living with mental ill health – a mental health nursing perspective

Abstract

Background: Uncertainty in illness is a well-known concept in health care literature. A considerable volume of research has investigated how people adapt to different health conditions and how the concept of uncertainty in illness relates to those populations. However, while there is substantial literature focusing on coping strategies and personal recovery, there is a paucity of research about uncertainty in illness among people living with mental ill health.

Aims: To explore the concept of uncertainty in illness among mental health nurses and to provide an understanding of its relevance to people living with mental ill health.

Method: Thematic analysis of a focus group of mental health nurses.

Findings: Uncertainty in illness among people living with mental ill health exists and manifests itself in various ways: uncertainty in the context of loss, uncertainty as a stimulus for change and uncertainty as an integral part of the human experience and existence.

Conclusions: Even though contemporary approaches in mental health nursing do not directly address uncertainty, the concept and its implications need to be considered and raised further among mental health professionals in order to improve support for people living with mental ill health in their process of personal recovery.

Keypoints

- Uncertainty is a multidimensional concept and a major part of any illness

- The concept of uncertainty in illness is not known among mental health nurses
- Uncertainty is seen in the context of loss and as stimulus for change
- Losses in a person's life are among the key challenges mental health nurses should be prepared to address
- Awareness for uncertainty in illness in mental health care needs to be raised

What is known about uncertainty in illness?

Uncertainty prevails in all human existence (Penrod 2001) and can be defined as a *"state or character of being uncertain in mind; a state of doubt; want of assurance or confidence; hesitation, irresolution" (OED 2019).* In relation to illness and specifically in nursing, Mishel (1990) defines uncertainty in illness as *"a fluctuation that begins in only one part of the human system […] (it) can either regress or cause no particular disruption or spread to the whole system. […] Uncertainty competes with the person's previous mode of functioning"(p.259).* However, the concept of uncertainty is used differently in the theoretical literature of several disciplines. This paper focuses on the nursing context. McCormick (2002) and Hansen et al. (2012) agree that uncertainty is a multidimensional concept and a major part of any illness that in its purest form is a "neutral cognitive state" (McCormick 2002, p.128). Feelings of uncertainty in illness are described as stressful and a burden, giving rise to fear and worry, unpredictability, ambiguity, inconsistency, vagueness and loneliness, whereas facing uncertainty seems to span the continuum from stress through reorientation and adjustment, acceptance, hope and even optimism (McCormick 2002; Hansen et al. 2012). In one of the few studies that focus on uncertainty in people living with mental ill health, the authors argue that people with schizophrenia experience uncertainty; not necessarily about the illness directly, but about how the situation will affect

their family, job or social networks (Baier 1995). Tan et al. (2014), investigating the experiences of people with early psychosis, consider uncertainty one of the main factors influencing the adaptation process to illness. Among their participants uncertainty caused hopelessness and feeling disconnected with their environment. However, apart from these two studies (Baier 1995; Tan et al. 2014) no other studies could be identified that refer to uncertainty from a service user perspective in other mental health conditions such as depression or others. Therefore, according to the available literature, uncertainty in context of mental ill health seems only to exist among health professionals or relatives but not service users. Additionally, the term "uncertainty" seems non-existent in the current literature about personal recovery in mental health.

Recovery and Uncertainty

The concept of recovery has been applied to areas such as physical disability and illness long before it was adapted to people who have a severe and persistent mental ill health (Anthony 1993). However, the term 'recovery'has several meanings in mental health: 'Clinical recovery' emerged from professional-led research and refers to an observable, clinical outcome that is rated by expert clinicians and usually means full remission of symptoms, whereas 'personal recovery' refers to a user-based understanding of recovery, which is individually defined and experienced (Slade 2009). The definition that still guides the current literature on personal recovery and mental ill health is: "*Personal recovery is a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness"* (Anthony 1993, p.20). Therefore, personal recovery is not what health care professionals do, but what people with

disabilities do for themselves, how they cope and adapt to their illness. Mental health nursing aims to help people access and review their private experiences in order to begin the healing of distress and to continue further human development and personal recovery (Barker and Buchanan-Barker 2005; Slade 2009). To what extent dealing with uncertainty in illness might be part of that personal recovery process remains unknown. Considering the vast literature around the topic of uncertainty in illness among other health conditions and how it influences health and wellbeing, it is important to find out more about uncertainty in illness in relation to mental ill health. To support people with mental ill health in their personal recovery it is important to understand all the different aspects which might influence that process. This may also include uncertainty and how to deal with these potentially stressful feelings.

Aim of the study

Within the deductive assumption that uncertainty in illness exists among people living with mental ill health as much as it has been described among other health conditions, the aim of this study is to explore mental health nurses' perceptions of uncertainty in illness in people living with mental ill health.

Method

A qualitative study comprising a focus group with mental health nurses was conducted. A focus group serves to explore participants' expertise, their knowledge, understanding and experiences about a predefined and limited topic (Kitzinger 1995; Robinson 1999). Additionally, the focus group method seems ideal to examine not only what the participants think but also how and why they think that way (Kitzinger 1995). Van Teijlingen and Pitchforth (2006) argue that the dynamic interactions within a focus group, the constant

negotiation of meanings is key to the data received and distinguishes focus groups from other group methods.

Ethics

All procedures were performed in compliance with institutional guidelines of the first author's university and in accordance with the International Ethical Guidelines for Health-related Research Involving Humans (CIOMS 2016). Additionally, permission to conduct the focus group was granted by the scientific committee of the international psychiatric nursing conference where the study took place. With the exception of the first author (lead facilitator) no member of the scientific committee of the conference nor any of the participants in the study had any previous affiliation with the project.

Sample and setting

Mental health nurses were chosen as participants. They are usually the ones who are seeing and interacting with service users 24 hours a day. In hospital settings, and even when they are working in outpatient or home treatment services, they are often in the position of supporting the service user through a crisis.

The focus group took place in the form of a workshop at an international psychiatric nursing conference and lasted 1 ½ hours. The setting enabled the inclusion of a broad and varied group of mental health nurses. Participants had to be willing to participate in the study and speak and understand English. As the focus group was held at a nursing congress and was open to registered attendees of the conference only, no further inclusion and exclusion criteria were used. Participants did not have to sign up for the workshop in advance and therefore, the number of participants remained unknown until it started.

Focus group

Participants received an information sheet and consent form as well as a demographic questionnaire with six topic specific questions at the beginning of the workshop. Participants were also informed verbally about the author, his intentions and the planned content of the focus group discussion. There was time for questions about the project including its methodology and participation was fully voluntarily.

The group discussion was led by the first author, who is a clinical nurse specialist in mental health nursing. He was supported by a senior nurse researcher in mental health nursing who also participated in the focus group discussion. A group discussion guide was used to remain focused on the topic.

Analysis

The group discussion was digitally recorded, transcribed and analysed using qualitative thematic analysis (Braun and Clarke 2006). The method describes several phases of the analysis that all have been performed in this study: In transcribing the data, mainly through paraphrasing, the first author familiarised himself anew with the data and noted down initial ideas (phase 1). Generating initial codes (phase 2) from what appeared to be most relevant to the analyst, and searching for themes (phase 3) in analysing the initial codes, led to a variety of potential themes or outcomes. Those were reviewed (phase 4) with the initial ideas and codes and then defined and named as main themes (phase 5). The final stage of the analytical process, producing a study report (phase 6), helped relating back to the aim of the study and the literature. The main themes were validated by one of the participants of the focus group. Vaismoradi et al. (2013) argue that thematic analysis provides researchers

with a clear and user-friendly method for analysing qualitative data due to transparent structures and defined analytical stages.

Results

Eleven conference attendees provided informed consent and participated in the focus group discussion. One participant chose not to share personal information as asked in the demographic questionnaire, but was still willing to take part in the discussion and have their contributions recorded and included in the analysis. The ten other participants represented six different European countries, eight were female and two males.

Eight pariticipants were nurses/mental health nurses, one was a psychologist working in mental health development and one was a health instructor working in mental health service user support. All participants had universitylevel education. The nurses had spent a median of 21 years (with a range of 6 – 32 years) in health care and nursing and were currently working in nursing management (n=2), nursing education (n=3), nursing practice (n=2) and nursing research (n=1).

All participants had either worked with, were still working with, or knew people with severe mental ill health such as major depression, schizophrenia or bipolar disorder. Nearly all had a friend or relative who had been diagnosed with a mental ill health and three participants considered themselves to have personally experienced mental ill health. Concerning the theoretical knowledge of the defined topic area, most participants (n=9) were familiar with the concept of personal recovery (Slade 2009) but no one was familiar with the concept of uncertainty in illness as described by Mishel (1988, 1990) or McCormick (2002).

Three main themes emerged from the thematic analysis; uncertainty in the context of loss, uncertainty as a stimulus for change, uncertainty as an integral part of the human experience and existence.

Uncertainty in the context of loss

People living with mental ill health often face a tremendous amount of loss; participants recalled reports and experiences of people who talked about complete loss of self and self-identity or, as someone described: “a mind shattered in a thousand pieces” (Participant (P) 7). Stigma related to mental ill health can lead to social isolation and exclusion and there is an increased risk of loss of employment, hobbies and friends. However, loss of social status is only one of many facets that people living with mental ill health may experience. Questions as profound as “who am I” or “what is happening to me?” easily create a tension of uncertainty and may cause hopelessness, fear and pain. Loss of identity strikes a person at the core of his/her existence: “This extremely talented and creative guy couldn’t tolerate the uncertainty of the diagnosis and couldn’t make sense of who and what he was anymore and killed himself”(P4). One of the participants who had a history of mental ill health herself recalled her loss of control and identity: “I couldn’t bear the uncertainty, I had to regain control over my life and reclaim who I am”(P9).

Uncertainty as stimulus for change

Sometimes action might arise out of uncertainty (as suggested in quotes above). This is supported by numerous contributions of participants who recollected experiences of service users they cared for or of family members and friends with mental ill health: “I felt that enormous drive for autonomy (in him)”(P8) or “she was determined to find something satisfying, useful growth and relevance in life”(P5). Negotiating uncertainties as a process was referred to as a learning experience, decision-making, soul-searching or simply as

making sense of what was happening. Uncertainty could be overcome by hope and taking action.

Uncertainty as an integral part of the human experience and existence

The discussion around the topic of uncertainty repeatedly returned to the understanding that it is nothing more and nothing less than a normal human experience and most likely prevails in all human existence: "it's part of who we are, with uncertain times in the world, the climate, politics etc"(P11). Participants mentioned various types of uncertainties that their service users or relatives with mental ill health experience and that were considered normal and understandable: "in that situation I would have felt the same, it's such an overwhelming experience with so many unknowns"(P10). However, it became clear that there is no single understanding of the concept of uncertainty.

These findings from the focus group with health professionals can be succinctly summarised by the following observation made by one of the participants: "Uncertainties (among people living with mental ill health) are the same as for anybody else except maybe more extreme…"(P9).

Discussion

The results of this study suggest that uncertainty is indeed an aspect of experiencing mental ill health. However, it seems that uncertainty manifests itself in more ostensible issues such as experiences of loss. Among those experiences, loss of identity might be the most difficult one. Strauss (1975) proposed that when living within an uncertain illness trajectory, *"a person's view of his trajectory and the shifting social relations that may occur as it progresses can profoundly affect his sense of personal identity" (p.52).* Such impact might be greater still

if there is stigma attached to the illness or symptoms. This is in accordance with some of the reports in this study of people who have experienced loss of self or identity along with a shift in personal relationships. These experiences are often interwoven with experiencing stigmatisation. Stigma experiences in the context of mental ill health are common (Rüsch et al. 2005) and often painful and have an impact on self-awareness and identity that need to be addressed (Amering and Schmolke 2012). Therefore, identity seems to be one of the most important aspects to look at in dealing with mental ill health as Slade (2009) suggests in his four tasks of recovery where developing a positive identity marks the first task. According to Buck et al. (2013) the *"discomfort elicited by the loss of, or threads to, a previous sense of identity"(p.136)* and the realisation of concrete losses in a person's life are among the key challenges mental health professionals should be prepared to address in assisting recovering persons with serious mental ill health. Loss of control or loss of identity may easily compromise one's ability to feel or stay safe. Barker (2005) argues that a person has a fundamental need for security, both existential and physical and that within the context of mental ill health this sense of safety and security might need to be regained. This could be achieved by supporting an individual to draw upon their existing personal and interpersonal resources. Slade (2009) suggests that by promoting well-being and supporting goal-planning mental health professionals can help developing a positive identity in people living with mental ill health. Dealing with identity issues and losses are important aspects in the adaptation process to mental ill health, a process that may go hand in hand with feelings of relief but also fear and uncertainty (Buck et al. 2013).

In mental health, recovery is seen as an individual journey and the progression from the limitations of illness into "*a satisfying and fulfilling life, despite psychiatric symptoms"* (Schmolke et al. 2016, p.100). In that process uncertainty can be a stimulus for change as it

ranges from feeling hopeless and lonely to facing it through hope and willingness to reprioritise aspects of life (Hansen et al. 2012). Therefore, uncertainty could be seen a driving force for a new beginning or a new outlook in life and may lead to hopefulness. Hope is often seen as one of the key factors facilitating recovery in mental health and without hope, recovery is considered not being possible (Slade 2009; Amering and Schmolke 2012). Within the individual journeys of recovery of people with mental ill health the right support at the right time is essential. This can only be achieved by recovery-oriented, person-centered mental health practice that includes service user involvement and self-determination based on the concepts of empowerment and shared decision-making (Schmolke et al. 2016). However, within that, the focus on uncertainty in illness is still missing. Recognising and naming uncertainties could be a good starting point in a professional relationship between a service user and a mental health nurse. Identifying uncertainty is important to provide accurate and realistic information and share knowledge that may help to reduce anxiety and stress in service users (Hansen et al. 2012). Therefore, recognising uncertainty and helping service users dealing with them and moving beyond them, could be a valuable intervention mental health nurses can offer.

In summary, the lack of literature on uncertainty in illness among people living with mental ill health might be due to the profound and wide-ranging impact of mental ill health. The categories or themes that account for experiencing uncertainty are diverse, broad and multi-layered as the data from this study suggest. This is in accordance with Hansen et al. (2012) who found that uncertainty as part of illness *"is explained by several individual issues such as physical health, treatment, family, hope, self-understanding and/or control"(p.274)*, all issues that were referred to in this study as well.

Limitations

There are limitations to this study. The number of participants was small due to the single focus group discussion and therefore, the amount of data collected was limited and no data saturation was sought which might restrict its validity. Methodologically it could be questioned if another form of inquiry would have been more expedient, such as the Delphi technique (Keeney et al. 2001) that could have helped to gain a clearer consensus among a panel of experts. However, as it was not the intention to achieve consensus about the meaning of the concept of uncertainty in mental ill health, an exploratory approach using a focus group seemed appropriate.

Implications for Practice and Future Research

Findings from this study highlight the complexity of uncertainty in people living with mental ill health from a mental health nursing perspective. It suggests that recognising uncertainty and supporting service users in coping with them could be a valuable intervention mental health nurses can provide. However, to do so the concept of uncertainty in illness should be better known among mental health professionals. This study will form the basis for further research into the topic of uncertainty in mental ill health. Especially relevant is research on service users' experiences, as from a nursing perspective it is important to take service users' experiences into account and link them to nursing interventions to achieve best practice (Hansen et al. 2012). Research such as this is intended to raise awareness of and encourage discussion about the issue of uncertainty in mental ill health particularly among mental health nurses who care for people living with mental ill health. Understanding the social, emotional and spiritual impact of mental ill health on daily life and its influencing factors such as uncertainty will help nurses to better provide holistic nursing care. Neville (2003)

concludes that *"assessment and intervention to manage uncertainty, when possible, are vitally important aspects to providing comprehensive nursing care to the individual and family faced with illness"(p.213)*. Interventions to manage uncertainty depend on the issue or theme that is linked to uncertainty in the individual situation. It is part of the first authors' current research project to identify those issues and themes for people living with mental ill health and how they influence their individual adaptation process to illness.

Conclusions

The findings of this study support the original deductive assumption that uncertainty exists among people living with mental ill health and that it is an integral part of their experiences in the context of mental ill health. This is well supported by statements and expert knowledge from the study participants, including those who had experienced mental ill health themselves.

However, there is a need for further research focusing on experiences of people living with mental ill health to highlight the issues they consider important and relevant in their adaptation process to illness and in personal recovery. It is this anticipated knowledge that will bring the concept of uncertainty in mental health care to the fore and highlight its relevance and importance.

References

Amering, M. and Schmolke, M., 2012. *Recovery - Das Ende der Unheilbarkeit*. 5. Auflage edition. Bonn, DE: Psychiatrie Verlag.

Anthony, W. A., 1993. Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal*, 16 (4), 11.

Baier, M., 1995. Uncertainty of illness for persons with schizophrenia. *Issues in Mental Health Nursing*, 16 (3), 201-212.

Barker, P. J. and Buchanan-Barker, P., 2005. *The tidal model : a guide for mental health professionals*. Hove, East Sussex, England ; New York: Brunner-Routledge.

Braun, V. and Clarke, V., 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3 (2), 77-101.

Buck, K. D., Roe, D., Yanos, P., Buck, B., Fogley, R. L., Grant, M., Lubin, F. and Lysaker, P. H., 2013. Challenges to assisting with the recovery of personal identity and wellness for persons with serious mental illness: Considerations for mental health professionals. *Psychosis*, 5 (2), 134-143.

CIOMS, 2016. *International Ethical Guidelines for Health-related Research Involving Humans*. Fourth Edition edition. Geneva, Switzerland: Council for International Organizations of Medical Sciences (CIOMS).

Hansen, B. S., Rortveit, K., Leiknes, I., Morken, I., Testad, I., Joa, I. and Severinsson, E., 2012. Patient experiences of uncertainty - a synthesis to guide nursing practice and research. *J Nurs Manag*, 20 (2), 266-277.

Keeney, S., Hasson, F. and McKenna, H. P., 2001. A critical review of the Delphi technique as a research methodology for nursing. *International Journal of Nursing Studies*, 38, 195-200.

Kitzinger, J., 1995. Qualitative Research. Introducing focus groups. *BMJ: British Medical Journal*, 311 (7000), 4.

McCormick, K. M., 2002. A concept analysis of uncertainty in illness. *Journal of Nursing Scholarship*, 34 (2), 127-131.

Mishel, M. H., 1988. Uncertainty in illness. *Journal of Nursing Scholarship*, 20 (4), 225-232.

Mishel, M. H., 1990. Reconceptualization of the uncertainty in illness theory. *Journal of Nursing Scholarship*, 22 (4), 256-262.

Neville, K. L., 2003. Uncertainty in illness: an integrative review. *Orthopaedic Nursing*, 22 (3), 206-214.

OED, 2019. "uncertainty, n.", *Oxford English Dictionary*. Online: Oxford University Press.

Penrod, J., 2001. Refinement of the concept of uncertainty. *Journal of Advanced Nursing*, 34 (2), 238-245.

Robinson, N., 1999. The use of focus group methodology — with selected examples from sexual health research. *Journal of Advanced Nursing*, 29 (4), 905.

Rüsch, N., Angermeyer, M. C. and Corrigan, P. W., 2005. Mental illness stigma: Concepts, consequences, and initiatives to reduce stigma. *European Psychiatry*, 20 (8), 529-539.

Schmolke, M., Amering, M. and Svettini, A., 2016. Recovery, empowerment, and person centeredness. *In:* Mezzich, J. E., Botbol, M., Christodoulou, G. N., Cloninger, C. R. and Salloum, I. M., eds. *Person centered psychiatry.* Cham: Springer International Publishing, 97-111.

Slade, M., 2009. *Personal recovery and mental illness : a guide for mental health professionals*. Cambridge: Cambridge University Press.

Strauss, A. L., 1975. *Chronic illness and the quality of life*. Saint Louis: Mosby.

Tan, R., Gould, R. V., Combes, H. and Lehmann, S., 2014. Distress, trauma, and recovery: adjustment to first episode psychosis. *Psychology And Psychotherapy*, 87 (1), 80-95.

Vaismoradi, M., Turunen, H. and Bondas, T., 2013. Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing & Health Sciences*, 15 (3), 398-405.

van Teijlingen, E. and Pitchforth, E., 2006. Focus group research in family planning and reproductive health care. *The Journal Of Family Planning And Reproductive Health Care*, 32 (1), 30-32.