
Negotiating uncertainty: an aspect of personal recovery in people living with mental illness

Abstract

Uncertainty in illness is a well-known concept among many health conditions including chronic illnesses. Much has been investigated in research in how people adapt to different health conditions and how the concept of uncertainty in illness relates to those populations. However, in mental health, even though there is an increasingly strong interest in coping strategies and personal recovery, the aspect of negotiating uncertainty has not been really investigated.

This paper explores the available literature, interprets its finding and puts them in context with the current developments in mental health nursing, e.g. personal recovery orientation.

Keywords

Negotiating uncertainty, uncertainty in illness, personal recovery, mental illness, nursing, adapting to life with mental illness

Background

Neither uncertainty in illness nor personal recovery in mental illness are new concepts but exist for more than two decades. However, uncertainty in illness has hardly been looked at in the context of mental illness or the process of personal recovery in people living with severe mental illness.

Uncertainty in illness

Uncertainty prevails in human existence (Penrod, 2001). Mishel (1988) originally described uncertainty in illness as “the inability to determine the meaning of illness-related events” and later specified that

Uncertainty in illness is viewed as a fluctuation that begins in only one part of the human system and according to chaos theory, can either regress or cause no particular disruption or spread to the whole system. ... Uncertainty competes with the person's previous mode of functioning. (Mishel, 1990, p. 259)

However, the concept of uncertainty appears in the theoretical literature of several disciplines and may be used slightly different in each one of them.

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Therefore, this paper focuses on the use in nursing only. McCormick (2002) and Hansen et al. (2012) agree that uncertainty is a multidimensional concept and a major part of illness that in its purest form is a neutral cognitive state. 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 be along a whole continuum from stress through reorientation and adjustment, acceptance, hope and even optimism (McCormick, 2002; Hansen et al., 2012). In a study focusing on uncertainty in people with schizophrenia the authors found that people with schizophrenia experience uncertainty, but not necessarily about the illness directly but about how the situation will affect family, job or social network (Baier, 1995).

Negotiating uncertainty

Negotiating uncertainty has been described as a transitional process of adapting to life with a chronic health condition. The findings of a grounded-theory study focusing on people living with HIV led to development of the Perrett and Biley Negotiating Uncertainty Theory (PB-NUT) which describes seven subcategories to the core category of negotiating uncertainty (Perrett and Biley, 2012):

- *Moving from denial to acceptance*
- *Strengthening through hope*
- *Moving from being controlled by the illness to controlling the illness*
- *Seizing opportunities*
- *Broadening vision: moving from self-focus to self-comparison*
- *Planning for the future: moving from escaping to distracting*
- *Existing as-was: moving from everything changing towards remaining*

The subcategories could probably be quite easily, at least partially, being matched with the four tasks of recovery as listed below. However, there is a need for further investigation if the PB-NUT could be adapted to other populations such as people with severe mental illness.

Personal recovery and mental illness

The concept of recovery has been quite common in areas such as physical disability and illness long before it has been adapted to people who have a severe and persistent mental illness (Anthony, 1993). The definition that still guides current literature about personal recovery and mental illness (Slade, 2009) has been introduced mainly by the writings of consumers, service users and so called “survivors” and is described as ... (Anthony, 1993):

... 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.

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Slade, M. (2009) *Personal Recovery and Mental Illness – A guide for mental health professionals*. Cambridge University Press, Cambridge, UK

Therefore, personal recovery is not what health care professionals do but what people with disabilities do for themselves. Mental health nurses can only facilitate recovery in the use of treatments and support that keeps the individual in their life (Anthony, 1993; Slade, 2009). Four recovery tasks can be identified (Slade, 2009):

- *Developing a positive identity*
- *Framing the “mental illness” (developing a personally satisfactory meaning to the experience)*
- *Self-managing the mental illness*
- *Developing valued social roles*

Additionally, four groups of tasks for mental health professionals are identified to support people in their process of personal recovery (Slade, 2009):

- *Supporting hope by fostering relationships*
- *Supporting identity by promoting well-being and goal-planning*
- *Supporting meaning by using the assessment process*
- *Supporting personal responsibility by offering interventions which foster self-management*

Barker & Buchanan-Barker (2005) argue that people with mental illness often experience distress, disturbance and a lack of control. 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 (Barker & Buchanan-Barker, 2005, p. 37).

Relationship between different concepts

Several studies have been conducted to focus on the relationship between different concepts such as coping and uncertainty but some have shown conflicting results (Homewood, 2001). Additionally, negotiating uncertainty and personal recovery are rather theoretical models or frameworks than concepts and both include several different concepts that could be compared with each other. One of those concepts is hope. Hope has been identified as a central aspect for the process of personal recovery in people living with mental illness (Slade, 2009) as well as in the process of negotiating uncertainty: strength can be found through the development of hope, which leads to being empowered (Perrett and Biley, 2012). However, Morse and Penrod (1999) argue that uncertainty may easily paralyze hope, as it is much more related to the course and process than to the outcome. Therefore, it might be essential to find out how a person can negotiate or deal with uncertainty and how that person could be supported in this adapting process. The relationship between different concepts will be part of the proposed study.

Aims

The aims of the proposed study are to identify the relationship between uncertainty in illness and personal recovery and how negotiating uncertainty is an aspect of the personal recovery process that needs to be taken into consideration for the support tasks of mental health nurses.

Methods

The full methodology of the study cannot be clearly outlined yet. It is planned to discuss the topic with an expert panel at the Horatio European Psychiatric Nursing Conference in Istanbul, Turkey, to gain further insights into the topic. Additionally, as part of an on-going pilot study focusing on goal-oriented nursing interventions and recovery on acute mental health units, it is intended to add questions about negotiating uncertainty in focus groups with patients. However, the latter has not yet been negotiated with the research team of the on-going study. Additionally, it might be helpful to use a grounded theory approach to further investigate into the topic area. One to one interviews, focus groups and the development or adaptation of a questionnaire are in discussion.

Discussion

Further investigation in the proposed topic area may show that the different concepts are not as far away from each other as it might seem at a first glance. It will be important to clarify how the different concepts are defined which may then lead to a similar and shared understanding of the terminology among health professionals or at least among the nursing profession. There is no doubt that experiencing uncertainty is an issue that can be found among most patient/user populations in health care and if there is common understanding of its dimensions and how to approach it as a nurse, this could change the personal recovery process from various groups of patients/users.