



“An Ongoing Struggle With the Self and Illness”: A Meta-Synthesis of the Studies of the Lived Experience of Severe Mental Illness



Charis P. Kaite*, Maria Karanikola, Anastasios Merkouris, Elizabeth D.E. Papathanassoglou

Cyprus University of Technology Department of Nursing, School of Health Sciences, Vragadinou, 3041-Limassol, Cyprus

ABSTRACT

The diverse experiences of severely mentally ill persons, most of the times, have not been taken into account, or integrated to the treatment procedures. This meta-synthesis aimed to examine what is like to live with severe mental illness narratives by employing a meta-ethnographic synthesis of seventeen published peer reviewed qualitative studies. Third order analysis revealed as core theme “An ongoing struggle for reconciliation with the self and the illness”. Other themes included amongst others: loss of identity, pain of having had one’s life stolen, being an outcast. The identification of the importance of the alterations of self-identity throughout the continuum of the severe mental disorder may be the focus of targeted psychosocial interventions.

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BACKGROUND

Despite the plethora of available treatment options for the management of severe mental illness (SMI), many are still in some point weakly associated with the lived experience of mentally ill people (Kent, 2003; Million, 2004; Thompson, 2007). Moreover, the treatment methods of mental disorders have not been developed in accordance to the special needs and wishes of mentally ill individuals (Barker & Buchanan-Barker, 2011; Jacobson, 2001; Warne & McAndrew, 2010). Thus, issues linked to quality of life and adherences to therapy are very often raised (Coring & Cook, 2007; Fleck, Keck, Corey, & Strakowski, 2005; Gale, Baldwin, Staples, Montague, & Waldram, 2012; Gee, Pearce, & Jackson, 2003; Haddad, Brain, & Scott, 2014; Manwani et al., 2007; Piat et al., 2009).

In relation to the lived experience of a situation, although many would argue that only an objective reality exists, according to Rogers (1959), what shapes a person’s behavior is not necessarily what is true, but “what the individuals thinks is true” (Nestoros & Vallianatou, 1996, p. 280). As a result, the person tries to perceive and conceptualize oneself in accordance with his/her perception of reality (Rogers, 1959). Under this scope, the way a person behaves in health and in illness issues, may also be influenced by his/her perception of the reality (Beck, 1991). Thus, the way one may react in relation to the therapy may be relevant to the way he/she interprets his/her illness and the treatment methods implemented (Beck, 1991).

Taking the above into consideration, one may assume that there are various contexts of reference in which to understand an individual’s lived experience of mental illness and its treatment. Indeed, previous literature focuses on specific aspects of mental disorder experience and from diverse backgrounds (Baker, Procter, & Gibbons, 2009; Green, Hayes, Dickinson, Whittaker, & Gilheany, 2003; Mauritz & van Meijel, 2009). In particular, a number of studies look at the lived experience of involuntary hospitalizations during the acute phase of the disease (Williams, 2008; Wood & Pistrang, 2008). In contrast, a vast amount of literature explores solely the lived experience of the recovery process (Aston & Coffey, 2012; Dilks, Takser, & Wren, 2010; Jensen & Wadkins, 2007; Turton et al., 2011), or the coping mechanisms used to combat mental illness (Green, Hayes, Dickinson, Whittaker, & Gilheany, 2002; Webb, Charbonneau, McCann, & Gayle, 2011; Yangarber-Hicks, 2004), whilst others investigate the ambivalent relationship between medication and quality of life (Gale et al., 2012; Piat et al., 2009; Sajatovic & Jenkins, 2007). Furthermore, some other studies describe the relationship between mentally ill people and health care professionals (Borg & Krinstiansen, 2004; Cleary, Hunt, Horsfall, & Deacon, 2012; Gahnström-Strandqvist, Josephsson, & Tham, 2004; McCloughen, Gillies, & O’Brien, 2011; Schroeder, 2012).

Despite the diverse objectives of studies on lived experience of mental illness, it is revealed that in most of them severely mentally ill people experience their disease as “a descent to hell” (Noiseux & Ricard, 2008, p. 1152), describing enormous suffering and exclusion from friends and families (Andersen & Larsen, 2012). The emotions frequently reported are shame, isolation (Liu, Ma, & Zhao, 2012) and powerlessness (Borg & Davidson, 2008). However, most of these studies do not shed light on the core of these experiences, and help us further understand the phenomenon of severe mental illness (SMI) and suffering in its essence (Andersen & Larsen, 2012; Borg & Davidson, 2008; De Maynard, 2007; Hirschfeld, Smith, Trower, & Griffin, 2005; Jönsson et al., 2008; Lee,

* Corresponding Author: Charis P. Kaite, PhD, Cyprus University of Technology Department of Nursing, School of Health Sciences, Vragadinou 15, 3041-Limassol, Cyprus.

E-mail addresses: charis.kaite@cut.ac.cy (C.P. Kaite), maria.karanikola@cut.ac.cy (M. Karanikola), anastasios.merkouris@cut.ac.cy (A. Merkouris), e.papathanassoglou@cut.ac.cy (E.D.E. Papathanassoglou).

Kleinman, & Kleinman, 2007; Liu et al., 2012; McCann & Clark, 2004; Moreira & Coelho, 2003; Nyström, Dahlberg, & Segesten, 2002; Nyström & Nyström, 2007; Pollack & Aponte, 2001; Sanseeha, Chontawan, Sethabouppha, Disayavanish, & Turale, 2009; Schön, 2009; Thompson et al., 2008; Wang, 2011; Ward, 2011). Overall, prior literature, theoretical explanations and historical perspectives present a variety of data regarding the lived experience of mental disorders, depending on the diverse study objectives, culture and backgrounds and structures of the health care systems (Andersen & Larsen, 2012; Borg & Davidson, 2008; De Maynard, 2007; Hirschfeld et al., 2005; Jönsson et al., 2008; Lee et al., 2007; Liu et al., 2012; McCann & Clark, 2004; Moreira & Coelho, 2003; Nyström & Nyström, 2007; Nyström et al., 2002; Pollack & Aponte, 2001; Sanseeha et al., 2009; Schön, 2009; Thompson et al., 2008; Wang, 2011; Ward, 2011). Moreover, it is through meta-synthesis that we can achieve greater understanding of the core of these experiences and shed some light on the phenomenon of SMI and suffering in its fundamental nature (Allen, Carpenter, Sheets, Miccio, & Ross, 2003; Barker & Buchanan-Barker, 2011; Barkham, 2002; Davies, 2014; Day et al., 2005; Deegan & Drake, 2006; Happell, Manias, & Roper, 2004; Hewitt & Coffey, 2005; Kieft, de Brouwer, Francke, & Delnoij, 2014; Kopelowicz & Liberman, 2003; Määttä, 2006; Malins, Oades, Viney, & Aspden, 2006; McCabe, 2004; Mueser et al., 2002; Yu & Kirk, 2008).

Although, a number of reviews on the subject of the lived experience of SMI exist in international literature, however, most of these studies have certain limitations. These are: inclusion of studies of solely one type of design i.e. phenomenology, focus on a particular aspect of the experience of SMI excluding others, inclusion of participants other than mentally ill people (family members or health care professionals), or no application of inclusion criteria or quality appraisal tools for the estimation of the rigour of the studies included in their sample (Andersen, Oades, & Caputi, 2003; Davidson, O'Connell, Tondora, Lawless, & Evans, 2005; Dundon, 2006; Holt & Tickle, 2014; Leamy, Bird, Le Boutillier, Williams, & Slade, 2011; Sells et al., 2004; Silverstein & Bellack, 2008; Warner, 2009; Wisdom, Bruce, Saedi, Weis, & Green, 2008; Zolneriek, 2011).

This paper aims to synthesize qualitative research findings that explore the lived experience of SMI in order to understand the phenomenon from a different angle compared to that of a single study's (Dixon-Woods & Fitzpatrick, 2001; Paterson, Thorne, Canam, & Jillings, 2001; Walsh & Downe, 2005). A novel synthesis of already given data has been attempted.

To the best of our knowledge this is the first study to synthesize studies that used a variety of qualitative methodologies in order to understand how people with SMI experience their disease.

METHODS

The present meta-synthesis encompassed three distinct phases: a) a systematic literature search, b) critical assessment of the selected papers, and c) a meta-ethnographic synthesis, according to Noblit and Hare (1988).

Search, inclusion and exclusion criteria

A comprehensive literature search was undertaken between May 2014 and January 2015 in the following Databases: CINAHL, MEDLINE, PubMed, Psych Info, Psychology and Behavioral Science Collection. The following search terms were used singularly and in combination in each database:

“mental illness” OR “mental disorders” OR “mental health” OR “serious mental illness” OR “severe and persistent mental illness” OR “chronic mental illness” OR “schizophrenia” OR “schizoaffective” OR “bipolar” OR “depression” AND “lived experience” OR “narrative” OR “self-stories” OR “life-history methods” OR “phenomenological hermeneutics” OR “autobiography” OR “ethnography” OR “interpretative phenomenological analysis” OR “subjective experience” OR “hermeneutic

phenomenology” OR “in depth interview” OR “qualitative research” OR “focus groups” OR “grounded theory” OR “open ended” OR “narratives” OR “perception of illness” OR “illness experience” OR “experiences and expressions” AND “service user” OR “client” OR “psychiatric consumer” OR “mental health consumer”

The studies included in the sample of the present meta-synthesis:

- 1) had been published i) from 2000 to present, ii) in the English language, and iii) in a peer-reviewed journal,
- 2) had a qualitative design,
- 3) were aiming to explore the lived experience or interpretation of severe mental disorder, including the process of recovery in their objectives, mainly bipolar disorder or psychosis,
- 4) were based on data that had been collected solely from individuals with severe mental disorders.

The studies that were excluded from the sample of the present meta-synthesis had the following characteristics:

- 1) The sample was limited: i) to people who were suffering from different types of severe mental disorder than psychosis or bipolar disease, such as OCD, substance abuse, postpartum depression, personality disorders or other types of DSM Axon II mental disorder, ii) to people who were homeless.
- 2) The samples were single person case-studies or included the life history of one person, due to certain limitations following these study designs, such as: a) the fact that the perspective regarding a particular phenomenon is limited and the results deriving from such study designs are difficult to be replicated, b) there is a greater risk, for “research bias”, compared to other types of qualitative study designs, since there are limited opportunities for assessing the rigorous of the results.
- 3) The aim was to investigate specific aspects of mental disorder experience, such as stigma, loss, grief, or specific aspects of recovery such as work, housing, medication management, as well as solely pre-diagnosis of first episode experiences, thus “recovery” was not included in search term.
- 4) studies that were evaluating the effectiveness of interventions e.g. art programmes, self-help programmes or clubhouse support
- 5) Data were based on narratives different than patients' perspective of the lived experience of severe mental illness (e.g. family members, mental health professionals or other therapists).
- 6) Dissertations because of the unavailability of data

The combined search strategies returned 1679 records. The titles, the abstracts, as well as the full texts were studied and 1568 papers were excluded. The remaining 111 papers, as well as 25 papers added after citation searching, were further examined in detail. After taking into consideration the inclusion and exclusion criteria, as well as the quality appraisal standards, 17 papers remained for the sample of the present meta-synthesis (Fig. 1).

Quality appraisal of retrieved papers

All the papers that were considered for inclusion in the sample of the present meta-synthesis were assessed in terms of methodological adequacy and rigor by the standardized tool Critical Appraisal Skills Programme (CASP). This is a form instrument that has been developed, tested and recommended by the National Health System of the United Kingdom (Schön, 2010).

The CASP tool provides classification of scholar papers according to their methodological adequacy. It consists of 10 items, each of them stating a question about a particular methodological feature. The first two items are screening questions and, if they are answered positively, the researcher is able to proceed with the remaining eight items, classifying the study in one of two quality categories. The questions can be answered with “yes”, “no” or “can't tell”.

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