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The experiences and meanings of recovery for Swazi women living with 'Schizophrenia'

Nxumalo Ngubane, S, McAndrew, SL and Collier, E

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The experiences and meanings of recovery for Swazi women living with 'Schizophrenia'

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Abstract

Introduction.

Globally, twenty-four million people live with schizophrenia, 90% living in developing countries. While most Western cultures recognise service user expertise within the recovery process this is not evident in developing countries. In particular, Swazi women diagnosed with schizophrenia experience stigma from family, community and care providers, thus compromising their recovery process.

Aim

This study aimed to explore the experiences and meanings of recovery for Swazi women living with schizophrenia

Methodology.

Interpretive Phenomenological Analysis was used. Fifteen women were recruited from Swaziland National Psychiatric Hospital out patients' department, and face to face interviews were conducted.

Findings

Four super-ordinate themes were identified: (1) The emotionality of 'illness of the brain'; (2) Pain! Living with the illness and with others; (3) She is mad just ignore her; and (4) Being better.

Discussion

Discussion focuses on the findings of this study and a number of positive and negative implications emanating from them; labelling, stigma and the roles of family, culture and religious beliefs on the process of recovery.

Implications for practice

This study provides practitioners with insight into the importance of the socio-cultural context of the lives of women diagnosed with schizophrenia and how, in understanding this, mental health care could be improved.

Key Words: Cross-cultural issues, Patient experience, Recovery Schizophrenia

Statement of Relevance: This study provides data supporting the provision of socio-culturally sensitive care both in Swaziland and developed countries where Swazi migrants may reside. More generally, it reinforces the importance of practitioners taking account of the socio-

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3 cultural context of people diagnosed with schizophrenia when assessing, planning and
4 providing care.
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8 **Accessible summary**

9 10 11 12 What is known on the subject

- 13
14 • While there is no single definition of the concept of recovery for people with mental illness,
15 hope has been recognised as a guiding principle; the belief that it is possible for a person to
16 regain a meaningful life, despite serious mental illness.
- 17
18 • Little is known about the recovery process of women diagnosed with schizophrenia per se,
19 with only six studies offering the woman's voice identified and these all having taken place in
20 developed countries.
- 21
22 • No studies on this topic have been carried out in Sub-Saharan Africa, including Swaziland.
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28 What this paper adds to existing knowledge

- 29
30 • This study provides unique insight into what is important to Swazi women, diagnosed with
31 schizophrenia, in their process of their recovery.
- 32
33 • Because of current trends in migration, the findings of this study may provide mental health
34 professionals with a better understand of the needs of those from this particular Sub-
35 Saharan country.
- 36
37 • The study discusses a range of issues affecting women including; being labelled as mentally
38 ill, stigma and discrimination, the importance of the socio-cultural context of illness and
39 positive attributes which promote women's recovery.
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45 What are the implications for practice?

- 46
47 • This study provides mental health practitioners with insights and understanding of the lives
48 of women from a Sub-Saharan developing country. This will be helpful for better
49 understanding of the context of mental illness both for practitioners supporting the
50 development of services in such countries, as well as those working in Western countries
51 with migrant populations.
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59 **Introduction**

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3 Globally, twenty-four million people live with schizophrenia, 90% of whom are reported to
4 be living in developing countries (McGrath et al., 2008; Myers, 2010). Men and women are
5 thought to be equally diagnosed with the illness (Saha et al., 2005), but their experiences of
6 recovery are likely to differ. While there is no single definition of the concept of recovery for
7 people experiencing mental health problems, hope is regarded as the guiding principle, with
8 the belief that it is possible for someone to regain a meaningful life, regardless of serious
9 mental illness (Mental Health Foundation, 2019). Definitions of recovery may be influenced
10 by gender, age, culture and socio-economic factors (Sajatovic et al., 2005). In recent years
11 there has been increased emphasis on service user expertise within the process of recovery
12 (Collier, 2010; Glover, 2012), however little attention has been given to this in developing
13 countries, such as those in Sub-Saharan Africa, including Swaziland (Burns, 2011).

24 Swaziland is situated in the southern part of Africa, with 95% of its border being with South
25 Africa, and 5% with Mozambique. It is a 17,363 km² landlocked country, with a population
26 of approximately 1.2 million people. Mbabane is the capital and largest city, and Manzini is
27 the second largest city situated at the centre of the country (Foreign Commonwealth Office,
28 2011). Swaziland is a Christian country, but also has traditional healers who are popular with
29 a high percentage of the population. Low-income countries, such as Swaziland, allocate only
30 a very small percentage of their overall health budget to mental health services. Whilst
31 specific data is unavailable, it is suggested that only 2% of health budgets in sub-Saharan
32 Africa are allocated to mental health, leading to underfunding in many countries (World
33 Health Organisation (WHO), 2011). This has resulted in 21st century mental health care
34 remaining institutionalized, as decentralization of services to the community requires more
35 financial resources (Saxena et al., 2007). Swaziland has only one psychiatric hospital,
36 situated in Manzini and serving the population, with a total of 6.8 mental health workers per
37 100,000 population (WHO, 2014). Of those admitted to the hospital, 33.9% have a diagnosis
38 of schizophrenia, with 26.4% being between the ages of 20-39 years, (Swaziland Ministry of
39 Health, 2010). Hospital admission can hinder the recovery process, as those using in-patient
40 services for long periods of time may experience dependency and learned helplessness
41 (Harrow & Jobe, 2012). In addition, a systematic review of international differences in
42 understanding recovery found little evidence of the concept of recovery being reported in
43 non-English speaking countries (Slade et al., 2012).

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3 In keeping with the global picture a diagnosis of schizophrenia in Swaziland is most
4 prevalent amongst 25 to 45 year olds, compromising productivity and adversely affecting the
5 country's economy (WHO, 2004). While both men and women contribute to the Swazi
6 economy, research in the United States indicates increased stigma and discrimination against
7 women who require mental health care (Manuel et al., 2012). Swazi women living with
8 mental illness commonly report physical, emotional and sexual abuse by men, with one third
9 experiencing sexual violence, thus hindering their recovery (Reza et al., 2009). This paper
10 explores the perceptions, experiences and meaning of recovery for Swazi women living with
11 schizophrenia with a view to improving the mental health care offered to them.
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20 **Reviewing the Literature**

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22 To date, and to the best of our knowledge, only five studies specifically focusing on the
23 experiences of women who have been diagnosed with mental health problems (Chernomas et
24 al., 2000; Ridgway, 2001; Manuel et al., 2010; McKay, 2010; Kalathil et al., 2011) have been
25 published, with a further study, Mancini et al. (2005), reporting on the experiences of men
26 and women. All five studies were conducted with women living in developed countries, and
27 although Kalathil et al., (2011) involved women of ethnic minority (African, South Asia, and
28 African-Caribbean) these were women living in the United Kingdom (UK) and exposed to
29 western culture.
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36 Two studies (Kalathil et al., 2011; Ridgway, 2001) defined recovery from mental distress and
37 psychiatric disability respectively within the psycho-social context of a woman's life. Such
38 definitions of recovery included; taking control of one's life, working towards personal goals,
39 desires and aspirations; having hope for the future; living independently; and being able to
40 secure a job, living a satisfactory life and making adjustments necessitated by the illness
41 (Kalathil et al., 2011; Ridgway, 2001). Two studies revealed that recovery occurred with
42 little professional support, but acknowledged that such support and the promotion of a
43 therapeutic environment could aid the process of recovery (Kalathil et al., 2011; Mancini et
44 al., 2005). Coercive treatment exacerbated fear and vulnerability, and was perceived as being
45 professional-led and not able to address service users' unique needs (Kalathil et al., 2011;
46 Mancini et al, 2005). Participants in a number of studies talked of being overwhelmed by
47 restrictions, leading to passive adjustment and acceptance of their illness being incurable, an
48 idea in keeping with a medically dominated perspective (Chernomas et al., 2000; Mancini et
49 al, 2005; Ridgway, 2001). McKay (2010) identified life with meaning was likely to enhance
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3 recovery. Meaning, in this instance, was established through setting realistic goals, assuming
4 social roles, developing insight, introspection, understanding and acceptance, engaging in
5 meaningful activities, and formulating a routine for daily life. Similarly, three studies
6 (Chernomas et al., 2000; Kalathil et al., 2011; Ridgway, 2001) indicated empowerment in
7 different areas of living can enhance recovery, including; the power to take personal
8 responsibility, focusing on inner strengths, self sufficiency, confidence, positive self image,
9 resilience and the ability to persevere.

10
11 Kalathil et al. (2011) emphasised the contribution of spirituality in mental health recovery.
12 African, Afro-Caribbean and South Asian participants' spirituality equated to trusting in God
13 and/or a belief in supernatural beings (Kalathil et al., 2011). Recovery from mental illness
14 was also found to have been enhanced, not only by trusting in God and/or a supernatural
15 being, but by the support given by members of the religious group participants identified with
16 (Chernomas et al., 2000; Kalathil et al., 2011; McKay, 2010).

17
18 While the research reviewed was all situated in western cultures, thus highlighting the lack of
19 research from developing countries, the aim of this research was to extend existing literature
20 by exploring the recovery process of women with a diagnosis of schizophrenia from a Sub-
21 Saharan context, namely Swaziland.

22 23 **Methodology**

24
25 Qualitative research adopting phenomenological interpretive analysis (IPA) was used for this
26 study. As the aim of this study was to explore the experiences and meanings of recovery for
27 Swazi women living with schizophrenia other qualitative approaches were deemed
28 inappropriate. Ethnography was not appropriate, as the principle researcher originated from
29 Swaziland and therefore familiar with the culture, and it would not have been practical for
30 her to live amongst and observe the culture. Additionally, there was no intention to generate
31 theory making ground theory redundant; and phenomenology as purely descriptive inquiry
32 would not satisfy the aim of the study. Phenomenology focuses on human experiences
33 through detailed descriptions of the phenomenon being studied (Creswell, 2003), while IPA
34 requires the interpretation of each nuanced story across a small group of participants (Brocki
35 & Wearden, 2006). IPA is particularly useful when exploring the inter-subjective nature of
36 experience (Smith et al., 2009).

37 38 *Ethics*

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3 Ethical approval was granted from the University of Salford (HSCR 12/33) and from
4 Swaziland National Psychiatric Hospital (SNPH). All potential participants were given a
5 participant information sheet, written in siSwati, outlining the purpose of the study, what they
6 would be expected to do, issues related to confidentiality, right to withdraw and what would
7 happen to the findings of the study. Informed consent was given by all participants.
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10 11 12 *Participants*

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14 SNHP staff working in the out-patient department (OPD) were briefed about the study and
15 asked to purposively select participants, based on their interactions with, and assessment of
16 people's mental state when attending the OPD. Staff handed out participant information
17 sheets, from which potential participants could ask questions of the staff or they could
18 contact the researcher directly.
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22 23 *Researcher*

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25 When undertaking qualitative research it is essential to consider the identity and
26 characteristics of the researcher (Tong et al., 2007). In this instance the researcher (first
27 author) is a Swazi women and a qualified mental health nurse. Currently living and working
28 in the UK, she spent five years working at the SNPH providing care to those diagnosed with
29 schizophrenia. From her experience the adequacy of care provision within the Swazi health
30 system, especially in terms of the recovery process for women diagnosed with mental illness
31 is concerning and was the impetus for this study. Whilst the researcher knew some of the
32 staff working at the hospital, she did not know any of the women she interviewed.
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40 41 *Data Collection*

42 Face to face interviews were conducted using a topic guide (Smith et al., 2009). Apart from
43 having a topic guide, the interviews were unstructured in order that the women's' accounts of
44 their experiences remained at the forefront of data collection, rather than them answering the
45 researchers pre-determined, and possibly biased questions. For example two questions used
46 as part of the topic guide were; 'What is your understanding of recovery?' and 'What
47 specific things, provided by SNPH, helped your recovery process?' The interviews were
48 undertaken in the siSwati language, so participants could clearly understand what was being
49 asked, and to ensure that they were better able to fluently and freely respond. All interviews
50 were audio-recorded, transcribed and translated into English by the first author.
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58 59 60 *Data Analysis*

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3 The seven steps of IPA were used; transcribing data verbatim, immersing self in the data,
4 initial noting, further identification of themes, identifying connections across themes,
5 analysing the remaining interviews and identifying patterns across all scripts (Smith et al.,
6 2009). From this process four super ordinate themes each of which were underpinned by a
7 number of subordinate themes were identified (see Table 1). Integral to this process was the
8 researcher's ability to use her experiences as a Swazi woman and as a mental health nurse,
9 gaining an in-depth understanding of the participants' lived experiences, by interpreting their
10 narratives within the Swazi socio-cultural context.
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19 **Findings**

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22 Fifteen Swazi women living with a diagnosis of schizophrenia participated. Their age ranged
23 from 21 – 70 years old. In keeping with Swazi culture, most participants did not have a high
24 school education; only one attained a university degree. All participants had been receiving
25 treatment for more than two years; with one woman being in receipt of treatment for almost
26 40 years. At the time of interview all participants were considered mentally stable and
27 attending the OPD based at the hospital. All participants were given Swazi pseudonyms.
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33 Four super-ordinate themes were identified across all participants' stories. While the first
34 three themes relate more to the experience of living with schizophrenia, the fourth focuses on
35 their future lives. The themes identified are: (1) The emotionality of "*Sifo sengcondvo*" or
36 '**illness of the brain**', as this is what the women believed they were experiencing. (2) Pain!
37 Living with the illness and with others; (3) Luhlanya lolu, ungalunaki (She is mad just ignore
38 her); and (4) Kubancono (Being better). Each of these themes encompassed a number of
39 subordinate themes identified in Table 1.
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48 Place Table 1 here
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52 In siSwati the word schizophrenia is non-existent, even though the women's' clinical records
53 revealed a diagnosis of schizophrenia. The first super-ordinate theme: Emotionality of the
54 '**illness of the brain**', revealed that the name participants gave to their illness, "*sifo*
55 *sengcondvo*" was different from the one ascribed by professionals. Within this super-ordinate
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3 theme three sub-ordinate themes were evident; tension and stress, feelings of rejection and
4 being disheartened, and a changed self.
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7 While there is disparity between western diagnosis used by professionals and lay descriptions
8 of mental illness, medical explanations of their illness appeared contradictory;
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11 *“I saw things that are not there, my mother took me to Dr H, who told me that my*
12 *blood level was low, it does not reach my head... he said this makes me ill.”* (Winile)
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16 Dr H suggested Winile had poor circulation to the brain, implying her illness was associated
17 with a physical condition. Eli’s doctor informed her the illness was triggered by studying
18 ‘very hard’;
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22 *“Doctors told me that I was studying very hard when the illness started, I was doing*
23 *form three, and my books got lost just before we wrote the junior certificate*
24 *examinations in 1973”* (Eli)
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26

27 While the doctor informed Eli of the possible cause of her illness, she appeared dissatisfied
28 with the explanation. Eli believed the loss of her books was due to them being stolen and
29 used for witch craft. While in a western context this may well reinforce her having mental
30 health problems, in Swaziland there is a strong belief in ‘witch craft’ amongst students,
31 especially during examination time. Although medical diagnosis was not verbalised to the
32 women, but explicated through simplistic and arbitrary reasoning, what it failed to
33 acknowledge was the cultural context of the women’s mental state. Culture impacting the
34 women’s mental health, particularly with regard to stressors, was also evidenced by Pholile
35 who talked of unknown people being a trigger for her illness. She stated:
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44 *“Oh! I was terrified. I was terrified. This was when I returned from church. I saw that*
45 *there were people coming towards me, these people were fighting. Ye...t, yet what*
46 *really scared me was that one of the princes wanted me, and I did not want to, I was*
47 *terrified through him.”* (Pholile)
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52 For Pholile this experience was particularly stressful because of its cultural implications. She
53 lived in an area dominated by traditional cultural practices, a place where most of the Swazi
54 traditional ceremonies, such as the reed dance, are held. Also, most of the Swazi princes live
55 in this area and it is common for them to have four, five or six wives. Pholile associated the
56 onset of her illness with coming back from church, articulating the actual trigger as being the
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3 prince 'wanting her'. Pholile may have thought the prince wanted her for marriage, and as
4 most Swazis who go to church detest polygamous marriages, for Pholile, the thought of the
5 prince's 'wanting her' terrified her to an extent that it triggered her illness. Tholu believed the
6 trauma of having her trust betrayed led to an 'injury in the brain':
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11 *"I first got injured in the brain when my husband started having extramarital affairs.*
12 *This caused a lot of distress to me". (Tholu)*
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16 Participants talked about how the illness brought about changes to self including;
17 uncontrollable, dehumanising and/or risky behaviour. As a result of these changes,
18 participants experienced feelings of rejection. Salaphi stated;
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22 *"I started dancing.....getting out of the house in the night to dance, I was not*
23 *sleeping....I did not see, the person talking, seemed to be my relative, from my*
24 *mother's side, my grandmother, I was hearing all her voice, clear as when she was*
25 *still alive..... They then brought me to hospital, it happened that when they were*
26 *trying to get hold of me I was stubborn, I was very strong, I beat them, they tie me."*
27 (Salaphi)
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31 Salaphi's experience of hearing voices is a common symptom of schizophrenia, but the
32 voices did not cause her distress, rather she rejoiced at hearing her grandmother's voice.
33 However, this was unacceptable to her family and she was 'tied up and taken' to hospital.
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36 Within this super-ordinate theme, participants describe their experiences of the emotionality
37 of their 'illness of the brain', how the illness changed them and how these changes affected
38 their emotions and those of the people around them, to an extent whereby living with the
39 illness and others was perceived as 'painful.'
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44 Pain! Living with the illness and with others
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47 This second super-ordinate theme centred on not being listened too and misunderstood by
48 those around them; family and their community. Within this super-ordinate theme were four
49 subordinate themes; not being heard, the pains of traditional healing, exclusion from
50 communities and being hurt by professionals. Not being listened too was perceived as a
51 hindrance to their recovery. Salaphi stated;
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57 *"You see at home there is a traditional healer.....and a healing clinic. At*
58 *home they held me, forced me into the hut.....to eat the traditional healing*
59 *herbs, they smeared the herbs on my mouth while they held me, I did not want*
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3 *to eat their medicine, they forced me to drink the medicine..... I know myself,*
4 *and I know when I am sick, that time I was not sick at all, I was just being*
5 *accused of doing something I did not do.” (Salaphi)*
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9 While Salaphi experienced the psychological frustration of not being listened too by
10 her family, traditional healers also inflicted physical pain;
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15 *“When it started I could go to..... traditional healers, they beat me and beat me,*
16 *then I would come to hospital swollen all over my body. Hawwuuu!!!!!! It was so*
17 *painful.” (Winile),*
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20 At a community level the women also met with disdain from others. Felaphi talked of
21 how her absence from church was blamed for her daughter’s pregnancy:
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25 *“I experienced a great brain injury from my pastor who did not support me when my*
26 *daughter became pregnant before getting married..... During his home visit, the*
27 *pastor attributed my daughter’s premarital pregnancy to the fact that I was no longer*
28 *able to attend church, and this really hurt me.” (Felaphi)*
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32 The above quotations demonstrate strong cultural boundaries within Swazi society which
33 women are expected to adhere to, regardless of their potential to precipitate illness.
34 Participants’ believed at times others, particularly health professionals, were paternalistic,
35 judgmental and sometimes used coercion to support their own ideas of recovery. Pholile
36 stated:
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41 *“Then they gave me an injection, I was not ill at all. I did tell the doctor (spoke with a*
42 *soft voice, with emphases) told the doctor that I was not ill, but they continued to hold*
43 *me and injected me..” (Pholile)*
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47 Within this super-ordinate theme participants seem desperate to be heard and frustrated at not
48 being listened too. They believed family, community, traditional healers and health
49 professionals alike, did not want to listen to them, but rather took a paternalistic stance of
50 knowing what was best for them and intervening accordingly.
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55 Luhlanya lolu, ungalunaki’: She is mad, just ignore her,
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3 The third super-ordinate theme, 'Luhlanya lolu, ungalunaki' transliterated as: 'she is mad,
4 just ignore her,' highlighted the humiliation created by being labelled. Participants talked
5 about how they felt 'tarnished' due to being excluded from certain groups, because of the
6 illness. Within this super-ordinate theme, the subordinate themes of discrimination at work
7 and seclusion of the mad, illustrated some of the challenges the women faced.
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13 Most participants encountered segregation from their family members, significant others and
14 society, often being labelled as 'mad'. Pholile acknowledged that she mistakenly took her
15 night medication in the morning, making her sleepy during the day. Rather than finding out if
16 Pholile was okay, or giving her support, her mother's uncle spread a rumour that Pholile's
17 sleeping pattern was altered, therefore she was mentally unstable. As a result Pholile was
18 forcefully taken to hospital;
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24 *"They said I am not well, I was said to be mad, they told lies about me, stating that I*
25 *was not sleeping well. They took me to the doctor and told him all this"* (Pholile)
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29 Pholile became known by the community as 'a mad lady', with the associated stigma not
30 only affecting Pholile, but also her children. Due to the stigma associated with the illness
31 some participants were not able to get meaningful employment, resulting in them only being
32 able to engage in small scale economic activities, for example selling vegetables in the
33 market which they found demeaning. Lack of meaningful employment resulted in
34 hopelessness and low self-worth. Selina stated;
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41 *"I feel that I am not contributing anything to the family and therefore a burden to him*
42 *because he is working. We tend to have arguments over food because I am not*
43 *working and therefore not bringing anything to the family. I wish I could work and*
44 *make some money, especially to be able to take care of my one year old child".*
45 (Selina)
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49 Thobile approached her employer asking if she could be allowed to return to work gradually,
50 but he was sceptical.
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54 *"I want my employer to allow me to do things gradually, he should not tell me to stop*
55 *working, but should let me do things at a slower pace. I have spoken to my employer*
56 *and suggested this, he told me to wait, and thinks that I am still not feeling well.*
57 *My employer has not told me when I would be welcomed to go to work."* (Thobile)
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3 In contrast Salaphi worked as a child minder for a professional school teacher and chose to
4 inform her employer that she was living with the ‘illness of the brain’. This was important as
5 she needed to be excused to attend her monthly hospital appointments. However, while she
6 initially faced resistance from her employer, who would not let her go to hospital for monthly
7 reviews, Salaphi did not give up and persisted until her employer accepted the situation and
8 gave her permission to attend her hospital appointments.
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14 *“At first she was a bit difficult, she was refusing to let me attend the hospital for my*
15 *monthly visit, but then she later realized that her refusal was not helpful.” (Salaphi)*
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20 While Salaphi retained her job as a child minder after disclosing her illness, Eli lost her job as
21 a pre-school teacher, being immediately replaced by another teacher as soon as it was known
22 she was diagnosed with mental illness. Not being able to work led to frustration due to a
23 scarcity of income, and while some participants strove to overcome this by setting up their
24 own business, this strategy often took time to come to fruition.
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30 Stigma was not only restricted to employers, families and communities, Pholile experienced
31 nurses and doctors prejudice toward people living with the ‘illness of the brain’, an attitude
32 that may hinder recovery. Five participants felt strongly about, what they described as their
33 dreadful experiences in seclusion. For example, Welile described the state of seclusion as
34 follows;
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40 *“There is no bed in seclusion..... not even given a mattress to sleep on. They just give*
41 *you blankets, you have to spread them on the floor and sleep on the concrete. It is*
42 *terrible in winter when it is so cold, you still have to sleep on the cold concrete, it is a*
43 *terrible place.” (Welile)*
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47 For the participants in this study seclusion impacted on their emotional wellbeing. A number
48 of participants felt that the decisions for secluding them were not justified and distracted from
49 their recovery. Being labelled as ‘mad’ led to participants’ feeling humiliated and shameful.
50 This label was reinforced through segregation from family, community and employment and
51 for many, their seclusion by professionals. For the women in this study the latter led to low
52 self-esteem, believing they could not achieve anything beyond what they have, and as such
53 they described their recovery is in terms of ‘going back to normal.’
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Kubancono (Being better)

The final super-ordinate theme brings to light the unique aspects of their lives they felt promoted their recovery. This encompassed the subordinate themes of: Having faith in; self, medicine and religion; nurtured by loved ones; we shall overcome and being useful, wanted and valued.

For the participants having faith in self, the professionals providing care and their religion were all important facets in their recovery process. Participants believed they were best placed to know when they had recovered;

“Feeling better is when I feel that I am better” (Winile).

“My last proper admission was in 2009, at that time I was really not feeling well, that was the last time I was not feeling well, I have recovered ever since.” (Nono)

Although some of the participants had experienced distress when in hospital, others found solace from the staff. Titi said; *“People in this hospital are good, even in the wards everything is alright;”* Lulu said; *“I also benefited from talking to a certain lady, a member of staff from ward X”*.

Finally within the subordinate theme of having faith a number of women also talked about how their religion had contributed to their recovery. For example Nono stated;

“I joined a Christian church in my community; I received so much help there as well. I attend church there; I clean the church, and attend prayer meetings every Monday where I pray with other members of the church, they pray with me, I feel better.”

In the next subordinate theme almost all the participants acknowledged the important role played by both their families and members of the community in their recovery process.

Tenele talked of how her family regularly supported her;

“I live with my mother and sisters. My mother provides me with food; she takes good care of me. My mother gives me food even at night when I feel hungry. My sisters support me financially; this pays for my transport when I come to hospital for monthly check up, and for my fare going to church” (Tenele).

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3 With support from the various sources identified above, the women found motivation to
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5 overcome their illness. Finally within this super-ordinate theme, the participants' needed to
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7 be useful, wanted and valued. Tholu said;

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10 *"I am involved in a community project that helps to feed the orphans. I have been*
11 *chosen to be in charge of the women who cook in the community kitchen for these*
12 *children, and my responsibility is to make sure that the orphans are well fed.... I feel*
13 *very happy about being part of this project."* (Tholu)
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16 In the process of their recovery families and significant others played an important role by
17 providing emotional and financial support. Participants also verbalised that they felt better
18 when accepted and able to contribute to their family and community. Health professionals
19 were acknowledged for their contributions to the participants' recovery which included;
20 spending time with them, talking with them, encouraging them to be involved in hospital
21 activities, and giving medication on time. It was all these aspects of life that led to
22 participants' feeling included, needed and valued.
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30 **Discussion**

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32 In Swaziland the general population would not be familiar with the term schizophrenia, but
33 tend to refer to any mental illness as 'illness of the brain', however mental health
34 professionals do use Western diagnostic categories, but these are not shared with service
35 users. One issue in naming schizophrenia as the 'illness of the brain' is that it is not specific.
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37 'illness of the brain' could be understood as anything from organic illness, for example,
38 epilepsy, to non-organic disorders, such as schizophrenia, depression. Recovery from non-
39 specified illness could possibly be hindered by inappropriate interventions and treatment
40 (Mezey et al., 2010). However, not being specific could also free mental health professionals
41 from restrictive practices, encouraging them to more carefully listen to the person's story
42 (Warne & McAndrew, 2008). For example, Salaphi talked of dancing in the house at her in-
43 laws and while this is out of keeping with cultural norms of politeness, it does not equate to
44 mental illness.
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54 A diagnosis of schizophrenia attracts stigma. It could be argued in not giving this label to the
55 women was a way of protecting them, as the term schizophrenia has been linked to feelings
56 of hopelessness, despair and despondency (Snowden, 2009). In contrast it could be suggested
57 that in knowing the challenges people have to face will promote the development of coping
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3 strategies that within the context of the illness will lead to a better quality of life (Ng et al.,
4 2008; Mezey et al., 2010). In this study medical influence, (diagnosis) affected the way in
5 which clinical staff interacted with the participants, the inclination being to treat symptoms
6 with medication, rather than focus on individual needs. Similar to the findings of Mezey et
7 al., (2010), the women in this study had a desire to take the lead in managing their illness, as
8 well as their medication, and to ultimately remain in control of their lives.
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14 The findings of this study demonstrate how cultural beliefs and values had an influence on
15 the women's perceptions of their 'illness of the brain'. The cultural context of a person's life
16 must be taken into consideration when caring for people living mental illness (Ng et al.,
17 2012). Previous studies (NHS Health Scotland, 2008; Kalathil et al., 2011; Ng et al., 2012)
18 have suggested service users do not benefit from health services because of either cultural
19 conflicts or exclusion of their cultural values in their plan of care. Consideration of cultural
20 practises and values were identified as being integral to recovery, with a number of studies
21 recognising the importance of staff's understanding and acknowledgement of diverse culture
22 when delivering care, and being flexible in order to meet service users' needs (McKay, 2010;
23 Manuel et al., 2012).
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33 The women in this study living with 'illness of the brain' experienced stigma. This is in
34 keeping with findings of previous studies (NHS Health Scotland, 2008; Armour et al., 2009;
35 Mezey, et al., 2010; Manuel et al., 2012; Bromley, et al., 2013). Sources of stigma for the
36 women in this study arose from self; professionals, family members and society (Jenkins et
37 al., 2005; NHS Health Scotland, 2008). Such negative beliefs about self, and reinforced by
38 others, can lead to separation from community or society in order to avoid further humiliation
39 (Corrigan & Watson, 2002). Because of the above, stigma can hinder independence, promote
40 boredom and give rise to feelings of rejection and under achievement, all factors evidenced
41 by the women in this study and considered the antithesis of recovery (Ridgway, 2001).
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50 For participants in this study, stigma and in particular discrimination at work, led to financial
51 constraints and an inability to meet daily needs. Lack of employment amongst people living
52 with mental illness is problematic as the socio-economic consequences may include poor diet
53 and homelessness (Manuel et al., 2012; Bromley, et al., 2013). Although evidence suggests
54 people living with mental illness are capable of sustaining their employment, even though
55 they could still be experiencing symptoms, it appears that some employers in Swaziland still
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3 have negative attitudes towards them (Albert et al., 2011). Employers need to be sensitized
4 and educated about mental illness and how best to work with people who have had such
5 experiences (Rethink, 2003). Positive action needs to be taken with regards to changing
6 societal attitudes in Swaziland. For example, in Swaziland the Government could provide
7 financial incentives to support employers in employing those who have recovered from
8 'illness of the brain'. In Germany Angermeyer and Matschinger (2005) found attitudes of the
9 public towards people living with schizophrenia were positively changed after they (public)
10 were given information and education.
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19 In developing countries, families and significant others of people living with mental illness
20 often take a lead role in supporting them throughout their recovery journey (Thara et al.,
21 2007). In their study in Chennai, India, Thara et al. (2007) found that families taking on such
22 responsibility often felt it to be a strain and became distressed. Evidence in this study found
23 some families of Swazi women living with "illness of the brain" often had negative attitudes
24 towards them; for example, referring to them as 'mad women'. When considering Thara et
25 al.'s (2007) findings it could be suggested that the attitude of the family might have been
26 triggered by the stress, and perhaps associated stigma, of caring for someone who is mentally
27 unwell. The clinical importance of these findings indicates a need for compassionate support
28 for service users and their significant others. This would require professionals to work
29 together with the service user and her significant others to ascertain the level of emotional
30 support needed in order to address the psychological aspect of both parties' experience. In
31 short, the strategies for health services aimed at promoting recovery must look towards
32 working with service users and their significant others in restoring their mental wellbeing in
33 order that the former can regain a sense of self, and the latter can support them in doing this.
34 Similar to other studies undertaken among African participants living in developed countries
35 (Kalathil et al., 2011), the women in this study appreciated the positive contributions given
36 by their families in their recovery journey. The findings also revealed that the recovery of
37 Swazi women living with the 'illness of the brain' was enhanced by contentment, which they
38 gained from a number of sources, among which are; reflecting on previous accomplishments,
39 trust in God, and having hope that things would actually get better.
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55 **Conclusion**

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58 Effective mental health care cannot take place out of the socio-cultural context of a person's
59 life, if professionals are to enable those who experience mental illness to fulfil their potential
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3 through the process of recovery. Those participating in this study believed recovery from the
4 'illness of the brain' is possible, acknowledging that it is an individual unique process. Even
5 though they acknowledged impediments to their recovery, the majority of the Swazi women
6 in this study were hopeful that their situation could change for the better, with some
7 specifically narrating how they succeeded in dealing with some of the setbacks which were
8 likely to hinder their recovery. Despite all the negative untoward circumstances the
9 participants encounter, they were persistent in wanting to go beyond the limits of the illness
10 to become the best, for self and significant others. Harnessing such motivation in these and
11 other women living with the 'illness of the brain' could facilitate a new broader perception of
12 recovery within Swaziland and beyond. Perhaps, once empowered the women in this study
13 could not only pursue higher goals for themselves, but might also encourage others to do the
14 same, bringing societal change, and in the lives of Swazis and/or other sub-Saharan people
15 living with 'illness of the brain'.
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26 **Reflexivity**

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28 As a Swazi woman, mental health nurse and a researcher I was sensitive to the context of the
29 women's lives, a measure of authenticity in qualitative research (Yardley, 2000). Initially
30 some of the participants had difficulty in talking about their experiences, possibly because
31 they were meeting me for the first time, or they were revealing personal, maybe
32 embarrassing, painful, experiences. Using my skills as a mental health nurse and spending
33 time at the OPD working with the staff prior to starting the study, allowed me to establish a
34 rapport with potential participants, without having any pre-conceived ideas from knowing
35 their history.
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44 However, as I listened, read and re-listened and re-read the first three stories, I realised, I was
45 constantly referring to their experience of living with schizophrenia, yet none of the
46 participants talked about schizophrenia. This was due to my recent experience of working in
47 the UK and using language common to that context. Being reflexive I was able to realign
48 myself with the Swazi context, whereby mental illness per se is commonly referred to as
49 'illness of the brain'. This facilitated a shift in my thinking, from one of emphasising
50 'Western' illness, to focusing on the person within their given context. By sharing the same
51 words (language) it is hoped that the participants' voices were brought to the fore, perhaps
52 providing opportunity to develop a model of recovery specific to the context of Swazi
53 women.
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Limitations

There is limited African perspective information on mental illness and recovery. In light of this the majority of information used in the literature review was based on developed countries, or other developing Asian countries (China, India) rather than African countries. While this qualitative study offers insight from a small number of participants (15) it is hoped that future researchers will be able to build on this in order to develop a substantial body of evidence. Using two languages, and subsequently translation and transliteration, in a qualitative research study and keeping fidelity to the women's' narratives was also challenging.

Relevance for clinical practice

While this study was carried out in Swaziland current trends in migration, particularly in Europe, Australia and Canada would indicate its potential usefulness in other such countries. However, further research is needed, particularly in relations to comparative work in other areas of sub-Saharan Africa and/or looking at the experience of Swazi women with mental health problems living in Western countries. Mental health practice cannot take place out of the socio-cultural context of a person's life, as in doing so one may condemn a person to a 'lifetime' of illness, rather than understanding of their position they place themselves in society. Mental Health professionals have the capacity to view people living with the 'illness of the brain' and/or schizophrenia as having the potential to fulfil their goals and aspirations and, in demonstrating understanding of this through their clinical practice, will instil hope. Women living with 'illness of the brain' need to be recognised as experts in their own right and therefore best placed to educate others about their experiences of living with a mental illness and what hinders or promotes their recovery.

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Table 1 Super-ordinate and subordinate themes

Super-ordinate themes	Sub-ordinate themes
The emotionality of the 'illness of the brain'	The 'illness of the brain' Changed self and feelings of rejection and desperation Tension and stress of the experience
Pain! Living with the illness and with others	Family & community, e.g. police Hurt by staff
Luhlanya lolu, ungalunaki (she is mad, just ignore her)	Rejected by Family & segregated by society (tarnished) Discrimination at work/employment Professional attitudes Seclusion
Kubancono (Being better)	It's up to me Family, significant others, community Hospital Religion Medication (willingly, following the rules) Motivation to overcome Assertive Productivity & contentment Being valued & wanted