

Lived Experiences of Young People who Live with Mental Healthcare Users in Limpopo, South Africa

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Abstract

Mental illness is more than just the diagnosis to an individual – it also has an impact on the social functioning of the family at large. When a parent or relative has a mental illness, all other family members are affected, even the children. The purpose of the study was to provide insight into the lived experiences of young people who live with mental healthcare users and the way in which their daily coping can be maximised. A qualitative, descriptive, phenomenological research was undertaken to explore and describe the lived experiences of young people who live with mental healthcare users in the Limpopo province, South Africa. Audiotaped, unstructured in-depth interviews were conducted with 10 young people who grew up and lived with a family member who is a mental healthcare user in their homes, until data saturation was reached. A content analysis was used to derive themes from the collected qualitative data. Four major themes emerged as features reflective of the young people's daily living with mental healthcare user, namely psychological effects, added responsibilities, effects on school performances, and support systems. This study recommends that support networks for young people be established through multidisciplinary team involvement and collaboration and the provision of burden-sharing or a relief system during times of need. With the availability of healthy coping mechanisms and support systems, the daily living situations and coping of young people could be maximised, thereby improving their quality of life while living with their family members with mental illness.

Keywords: family, mental healthcare users, mental illness, lived experiences, young people



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Introduction and Background

Global mental health reforms to improve mental healthcare services brought about various forms of restructuring in mental healthcare services.

A dramatic change brought about by the introduction of deinstitutionalisation as a policy strategy, whose intention was to make use of established community-based facilities for further care, aimed at reducing the number of acute or sub-acute inpatient beds in psychiatric institutions. This strategy implementation yielded noticeable success with first-world countries that ensured it is accompanied by the establishment of community-based psychiatric units (Botha et al. 2010). But in South Africa, as in other developing and underdeveloped countries, pursued deinstitutionalisation met with various challenges that had negative effects on mental healthcare users (MHCUs) and their families. Shortages in both human and material resources led to MHCUs' brief hospital stays, and, in some instances, premature discharge to accommodate those who were more seriously ill. Inadequate community resources or the absence thereof in some cases, led to stigmatisation of patients in the community, high levels of patient abuse, homelessness, and recurrent readmissions (Botha et al. 2010). Families were left with no option but to care for their mentally ill members.

Research has widely shown that having a family member diagnosed with a psychiatric illness is a risk factor for poor family functioning. Studies on the experiences of family members who care for MHCUs by Magadla and Magadla (2014) and Mavundla, Toth, and Mphelane (2009) reveal adverse effects in physical, social and psychological aspects of the family. The family is required to reorganise its household routines, often with detrimental effects on its finances, social relationships, and leisure opportunities. The situation becomes more challenging if young people assume sole responsibility for the care of the MHCUs. Young people, being at their critical life period coupled with various developmental challenges are greatly affected. A shift in their attention on developmental issues such as dating and the formation of friends to that of caring for MHCUs adds much emotional strain and stress which are aggravated by the stigmatisation they face from the children who come from families not affected by mental illness and the community at large (Magadla and Magadla 2014). Caring for MHCUs may lead to role confusion as the young people are expected to carry out adult roles (Venkatesh et al. 2016).

Statement of Research Problem

Mental illness has an impact on more than just the individual; when a parent has a mental illness the impact of the illness is felt by other family members, in particular his/her children. Psychiatric care institutions have not adequately paid attention to the vulnerability of children and young people living with MHCUs as much focus has been on supporting the adult family caregiver. The researcher, who is the first author, studied young people who accompany their relatives for follow-up reviews and

outpatient treatment in a primary healthcare centre in the Limpopo province. Many of them exhibit anxiety, stress and uncertainty about the care and management of their relatives. Young people who are supposed to be at school on those days, miss classes which could have negative outcomes on their academic performances.

Empirical reviews affirm the impact that living with a mentally ill family member has on a young person's coping, life style and growth, and that too few accounts from the young people themselves of their lived experiences have been explored and the way in which psychiatric care units respond to the needs of these young carers (Marimbe et al. 2016; Venkatesh et al. 2016). Based on these premises, the researcher seeks to investigate and understand the way in which young people aged between 18 and 24 years' experience their daily life in a family with an MHCU so as to provide recommendations on the way in which they could be supported to improve their quality of life.

Purpose of the Study

This study sought to gain insight into the lived experiences of young people living with MHCUs in one district of the Limpopo province and the way in which their daily coping can be maximised.

Research Objectives

The following objectives were used to attend to the purpose of the study:

- to explore and describe the lived experiences of young people who live with MHCUs; and
- to identify and recommend coping and support systems for young people who live with MHCUs.

Definitions of Key Concepts

Mental healthcare user (MHCU) is a person who receives care, treatment and rehabilitation services or uses a health service at a health establishment aimed at enhancing the mental health status of the user (South Africa 2002). In this study an MHCU will be a family member, such as a parent, aunt, uncle or even a sibling, who has been diagnosed with a mental illness and who is on psychiatric treatment living with an adolescent aged between 18 and 24 years.

Young people refer to individuals between the ages of 15 and 24 years (UNESCO 2015), and the term sometimes refers to adolescents. In this study, the term young people will be used interchangeably with adolescents to mean individuals between the ages of 18 and 24 years who live with MHCUs.

Research Method

A qualitative descriptive phenomenological research was undertaken to explore and describe the lived experiences of everyday life of young people who live with MHCUs. Through in-depth interviews of the study participants, the researcher could gain insight into the ordinary conscious experiences of everyday life of the young people who live with MHCUs.

Setting

The study was conducted in the Limpopo province of South Africa. The researcher spent time with the young people in their homes conducting in-depth interviews to gather data. In line with the phenomenological design, the natural setting allowed the researcher to learn more about the phenomenon of interest in the context of the participants' real world, in this instance, the everyday life experiences of living with MHCUs explored in their home setting.

Population and Sampling

The study population consisted of all young people who live with MHCUs in the Limpopo province. A total of 10 young people between the ages of 18 and 24 were purposively recruited to participate in the study (Table 1). The principal investigator (MMM) met the accompaniers of the MHCUs in the primary healthcare centre to request contact details of the young people who live with MHCUs to set up appointments with them and to request them to participate. The inclusion criteria were that the participants have lived with the MHCUs for more than 2 years and are between the ages of 18 and 24 years.

Ethical Considerations

Approval was sought and granted by the Higher Degrees Ethics Committee of the Department of Health Studies at the University of South Africa (663/2017) and the South African Department of Health. Permission was also sought from and granted by the authorities at the primary healthcare centre and the Dikgale Tribal Authority which was responsible for the area in which the young people live. The principal investigator explained the objectives of the study to the potential participants before they gave written informed consent to participate in the study. Confidentiality was assured by not using the participants' real names or any information that could be traced back to them. The right to withdraw from the study at any phase was continuously emphasised.

Data Collection Procedure

Unstructured interviews were conducted in the homes of the participants. The interviews lasted from 30 to 45 minutes and audiotaping was done with the participants' permission. The interviews started with the broad open-ended question: "How will you describe your experience of living with a mentally ill relative?"

Probing questions included, "Please tell me how did you cope with the situation?" and "What do you think could be done to assist you?" Data were collected until no new information emerged. Data saturation was realised with the eighth participant but interviews continued up to the tenth participant.

Table 1: Description of the study participants

Characteristics of the participants	
Number of participants	10
Age range (years)	19–20 (<i>n</i> = 3) 21–23 (<i>n</i> = 7)
Gender	Female (<i>n</i> = 5) Male (<i>n</i> = 5)
Schooling	High school (<i>n</i> = 6) Tertiary level (<i>n</i> = 2) Dropout (<i>n</i> = 2)
MHCU relative	Parent (<i>n</i> = 7) Sibling (<i>n</i> = 1) Uncle (<i>n</i> = 2)
Years living with MHCU	≤ 12 (<i>n</i> = 3) ≥ 12 (<i>n</i> = 7)

Data Analysis

A content analysis was used to analyse the collected data. Audio recordings of the interviews were transcribed verbatim and the data from interviews were analysed using the seven steps given by Colaizzi as described in Polit and Beck (2012). Four overarching major findings that best explain the daily life experiences of young people who live with MHCUs were identified.

Trustworthiness

Trustworthiness was assured in this study by having the second author independently coding similar transcripts of the interviews to confirm the emergent themes. The first author also did member checking with the participants to verify whether what had been noted down was an accurate account of their responses. The data collection was done by the first author only to ensure consistency. Adequate time spent with the verbatim audio recordings of the interviews using Colaizzi's steps of analysis ensured prolonged engagement.

Results

Four main themes emerged from the content analysis: (1) psychological effects; (2) added responsibility; (3) effects on school performance; and (4) coping strategies and support. These main themes and their subthemes are discussed below with verbatim excerpts from the interview transcripts that were used to verify and validate them (Table 2).

Table 2: Themes and subthemes

Themes	Subthemes
Psychological effects	Ashamed and embarrassed Feeling of despair Fear and guilt
Added responsibility	Burden of care Non-adherence to treatment
Effects on school performance	Poor academic performance and progress Resulted dropouts
Coping strategies and support	Individual coping mechanisms Being accommodating Avoid and ignore Smoking and alcohol abuse Support systems Family Community Economic factors

Psychological Effects

Behavioural manifestations of mental illness displayed by MHCUs during times of relapse had severe psychological effects on the young people. The emotional strain and stress that prevail in their home environment were shown through various emotions such as living in fear and anxiety about the relative and family's safety, feeling ashamed or embarrassed and feelings of guilt and despair. The following excerpts from the participants' responses illustrate these emotions:

One day I was from the school, he was sent to the clinic, on the way to the clinic, he ran away and undress himself on the street while running; I felt bad because he is my uncle and people are laughing at him. (P4, 22 years, male)

When my father broke our neighbours' windows insulting them of witchcraft, I feared that they would fight back and I had to go and ask for forgiveness on his behalf. (P1, 21 years, male)

Added Responsibilities

Most participants highlighted that caring for MHCUs is an added load to their responsibilities. Thus, Uys and Middleton (2010) assert that continuous long-term caregiving leads to significant stress that is often referred to as the family burden or the caregiving burden. This was explicit in the responses from the participants with parents as MHCUs:

I had to do all housework, such as cleaning, cooking and washing and I become exhausted and sleep. My mother is always demanding everything from me. (P3, 21 years, male)

We accompany my brother to the clinic and supervise him to take treatment. Sometimes he becomes sick walk throughout the night and we have to go out and look for him. (P7, 20 years, male)

Effects on School Performance

As most of the participants were still in school, they all attested to the way in which their daily living experiences affected their school progress. Burns and Roos (2016) affirm that poor school performance should be viewed as a symptom that reflects an underlying difficulty that must be identified and managed. In the instance of this study, this was aggravated by the added responsibility of living with MHCUs as described in the previous subthemes. Some of the participants said:

I failed three times at school; when in grade 10 my mother became ill and she was shouting and making a lot of noise and I was writing final examination. I also repeated grade 11 and grade 12. (P5, 23 years, female)

I started drinking alcohol to cope with what was happening at home and ended up leaving school. (P8, 21 years, male)

Coping and Support Systems

Coping refers to the process of striving to master environmental stressors or challenges (Uys and Middleton 2010). With the availability of healthy coping mechanisms and support systems, these situations could be successfully handled. The study participants, in the midst of their emotional strain and stress, highlighted the coping strategies they used in their daily living with MHCUs and their dire need for support. Some of these coping mechanisms led them to risky behaviours. These included, among other things, being accommodating, being in denial or to ignore or to overcompensate. These excerpts illustrate this:

I decide not to answer or argue with my father for fear that he could attack me. (P9, 22 years, female)

I thought if I go out with my friend and have alcohol drink, will come back and tolerate the situation at home and I ended up drinking a lot. (P10, 22 years, male)

Most participants yearned for supportive mechanisms that could provide relief and ease their caregiving burden. The participants verbalised these needs through the following quotes:

No one is giving us support. My other uncle who was giving us support has passed away. (P4, 22 years, male)

I need a nurse to give us information on how to take care of my mother and guide us on how to relieve stress. (P6, 19 years, male)

Discussion

The daily living experiences with MHCUs had many repercussions for the lives of the young people. The impact can be felt interwoven in the young persons' psychological, social and economic spheres. As revealed in this study, the emotional strain and stress fuelled by the unpredictable nature of the illness and behavioural manifestations of the MHCUs and also limited knowledge and skills to deal with these, pose a great challenge to the young people's emotional well-being. Various authors affirm that the continual family care brought about by the shift towards community care and deinstitutionalisation of people with mental illness has seen many family caregivers immersed in emotional strain and stress (Jeyagurunath et al. 2017; Marimbe et al. 2016).

Socially, the tremendous caring demand that is exhaustive in nature denies young people time to socialise with their peers and deprives them of their youthful life. The stigma families with MHCUs suffer in their society, in this case young people perceived to have been "contaminated" by their parent or relative's illness, compounds the problem of the lack of social engagement with peers leading to further social exclusion and marginalisation. This further increases the emotional trauma and highlights the vulnerability of the young people to mental distress (Bjorgvinsdottir and Halldorsdottir 2014; Hutchinson et al. 2016; Reupert, Maybery, and Kowalenko 2013).

The role reversal and role confusion deprive the young people of parental love and care as they are in turn expected to take care of their sick parent or relative. The significant caring burden in their daily life experiences of living with MHCUs results in neglect or lack of enough time to focus on schoolwork, hence many respondents in this study reported slow school progress and ages that are older than those for the grades (for example, a 23-year old still in grade 12) and ultimately dropping out of school. This further aggravates feelings of despondency and despair and may make

them susceptible to both externalising and internalising mental health problems such as depression.

Recommendations

The need for support systems to successfully buffer the negative impacts on the daily living with MHCUs cannot be overemphasised. Therefore, based on the study findings, the researcher recommends an improved community psychiatric care system to provide professional mental health support to the young people in the daily care of the MHCUs and that includes the following essential activities:

- Programmes for the preparation of MHCUs for discharge to involve all family members, including young people.
- Burden-sharing or a relief system for young people who are the sole caregivers of MHCUs. Motivation for respite care in 24-hour primary healthcare clinics in times of need, such as examination times, to ensure school progress for the young people.
- Day-care rehabilitation programmes at the nearby clinics to keep the MHCUs occupied.
- Initiating support groups for young people who live with MHCUs to share their experiences and to be equipped with skills to adapt to their family life.
- Psycho-educational programmes in schools to empower schoolgoing young people with knowledge on the diagnosis, aetiology, signs and symptoms, and the management of mental illness.

Limitations of the Study

This study was conducted in only one district of the Limpopo province. A comparative study on the way in which the psychiatric community health services in different provinces of South Africa deal with the needs of young people who live with MHCUs is recommended. The use of a small sample of 10 participants may lessen the generalisability of the study findings. Further longitudinal research is recommended with larger samples to explore the effects of living with MHCUs from early adolescence until later in life so as to relate earlier experiences with the later developmental effects on adulthood.

Conclusion

Young people as the future citizens and tomorrow's workforce need to lead a productive youthful life to fulfil these roles. A lack of support for their emotional well-being and their engagement in social, educational and economic opportunities

during this life stage can be a disinvestment in a country's public health. The provision of integrated community psychiatric services is key to promoting mental health of the young people.

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