

# THE IMPACT OF PROVIDING CARE TO RELATIVES WITH A SEVERE MENTAL ILLNESS: THE CAREGIVERS' EXPERIENCE

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**Abstract.** The purpose of this study is to explore the impact on Maltese family caregivers in providing care to a relative with a severe mental illness (SMI). Purposive sampling and in-depth semi-structured interviews were conducted with seven caregivers (four females and three males). The interview data were transcribed verbatim and analysed using Interpretative Phenomenological Analysis (IPA). Four themes emerged from the analysis, namely Range of Emotions, Increased Responsibility, Toll on Physical Health and Change in Lifestyle. This study demonstrates that the caregivers experienced a range of negative emotional and physical responses. Changes in their lifestyle were made, as caregivers provided complete care to their ill relative, as well as ensured that they came to no harm. Female participants tended to self-blame, attributing behavioural problems in the ill relative to their actions. Parent caregivers experienced distress regarding care provision in the eventuality that they suffered from ill health or death. Although parents acknowledged the support provided by siblings, they strived to cope by themselves, as siblings were perceived to have responsibilities of their own. The role of mental health professionals in such a scenario includes the understanding of the unique perceptions of family caregivers, as well as targeting any dysfunctional perceptions. Furthermore, caregivers should be made aware of entities that provide support within the community setting. Sufficient resources also need to be provided to ensure effective community support to family caregivers.

**Keywords:** severe mental illness, family caregivers, qualitative research, interpretative phenomenological analysis

## 1 Introduction

Severe mental illnesses (SMIs) such as schizophrenia, bipolar disorder and major depression are often devastating, having a significant impact on both patients and their families (Rose, Mallinson & Walton-Moss, 2002). The three aforementioned SMIs are included within the list of six leading causes of disabilities (National Alliance on Mental illness, 2013).

Due to the deinstitutionalisation process, an increasing number

of people with SMIs are living within the community (Vecchio, Stevens & Cybinski, 2008). It is estimated that 90% of individuals with a SMI receive ongoing practical and emotional support from family caregivers (Ostman & Hansson, 2000). While being the primary source of support, caregivers also strive to make sense of the mental illness (Rose et al., 2002). Such demands may affect the caregiver in a number of ways, amongst which emotionally, physically, financially and psychosocially (Idstad, Ask & Tambs, 2010). In fact, one-third to one-half of caregivers suffer significantly more from psychological distress and display a higher incidence of mental ill health when compared to the general population (Shah, Wadoo & Latoo, 2010). The responsibilities of caregiving, added to the pressures related to maintaining a family and an occupation, can lead to stress and burnout (Glendy & Mackenzie, 1998). Being highly stressed and burdened not only leads to a detrimental effect on the caregivers' and ill relatives' health, but may even influence the caregiver to abandon care (Caqueo-Urizar, Gutierrez-Maldonado & Miranda-Castillo, 2009). Additionally, the challenges that these caregivers endure in providing constant support to an ill relative is sometimes unrecognized and/or taken for granted (Jeon & Madjar, 1998). Conversely, while most empirical studies document the burden associated with caring for a person with a severe mental illness, Aschbrenner et al. (2011) have demonstrated the positive aspects of caring for these persons, citing aspects such as personal growth and gratification.

According to Petrie, Broadbent and Kydd (2008), relatively few qualitative studies have explored the "underlying dimensions of mental illness beliefs and more research could be useful in this area" (p.561). The present study aims to contribute to the extant literature by exploring the perspectives of Maltese caregivers regarding the impact of providing care to relatives with a severe mental illness. Such information may be of assistance when formulating local interventions that are effective in targeting the expressed needs of this group.

## 2 Methods

### 2.1 Participants

A qualitative phenomenological approach was used to provide an in-depth exploration of the unique experiences of the study participants. Purposive sampling was employed and family caregivers were recruited if they a) cared for a person who had schizophrenia, bipolar disorder or depression either continuously or intermittently over a period of three years (thus ensuring that the patient did have a SMI) b) had provided support to the ill relative for more than six months, and c) were aged 18 years and over.

The sample consisted of seven caregivers (four women and three

men) who provided care to their relatives with a SMI. The caregivers consisted of four parents, one spouse and two siblings, with the most common role being that of the mother of the ill relative. Two of the caregivers were not living in the same household as the relative having a SMI but were actively involved in their relatives' care. The participants, mean age was 63 years, with an age range of 61-84 years. The mean length of time for care provision to the ill relative was 12 years. The mean age of the relative with SMI was 49 years. Three of the ill relatives had schizophrenia while two had bipolar disorder and depression respectively.

## 2.2 Data Collection

Semi-structured face-to-face interviews were conducted in the participants' home setting. The interview schedule consisted of two sections. The first part enabled the collection of demographic data on both the participants and their relatives with a SMI. The second part consisted of seven open-ended questions, which explored the perceived impact of caring for a person with a SMI, the coping strategies used and their satisfaction with support services available to their ill relative and themselves. Two pilot interviews were conducted with two female caregivers of persons with SMI. The interviews lasted approximately 50 minutes and the participants encountered no difficulties in completing them. The actual study interviews were then conducted with the participants and lasted about 45 minutes.

## 2.3 Ethical Issues

Approval to implement the study was obtained from the University of Malta Research Ethics Committee. The aim and nature of the research study was first explained to potential participants by a senior member of staff from the Community Mental Health outreach team. This was done to ensure that the caregivers did not feel coerced to participate. An information letter explaining the purpose of the study and highlighting caregivers' voluntary participation and their right to withdraw from the study at any point was provided. Written consent was obtained from every participant. Those caregivers who agreed to participate were contacted by the first author and additional queries were addressed. A pseudonym was assigned to every caregiver and all information collected was stored in a locked cabinet, to safeguard participant confidentiality. A psychologist was also available to provide support, in the event that any participant experienced distress during the interview.

## 2.4 Analysis

Interview transcripts were analysed using Interpretative Phenomenological Analysis (IPA), using the procedures outlined by Smith, Flowers and Larkins (2009). Accordingly, the first analytic stage involved the audio-recorded interviews being transcribed verbatim and the transcriptions re-read to get a sense of the participants' experience. The second step involved reading and noting down significant points related to the caregivers' experiences. These points were then used to document emergent themes. The connections among these were identified to formulate clusters of themes.

## 3 Results

Four major themes incorporating aspects related to the impact of providing care to relatives with SMI emerged, namely Range of Emotions, Increased Responsibility, Toll on Physical Health and Change in Lifestyle. Selected excerpts from the interview transcripts are provided to illustrate these themes. Text within square brackets represents clarifications provided by the authors.

### 3.1 Range of emotions

All caregivers described the range of emotions experienced when caring for a relative with a SMI. These emotions included feelings of loss, sadness, excessive worry, guilt, frustration and burnout. The sadness experienced was intensive and caregivers yearned for the past, as described in the following excerpts.

*"I am hurt because I want him the way he used to be, just the way he used to be before, that he walks properly at least. This is because now depression has set in and he has ended up physically like this ... I wish that all my troubles would just disappear and everything returns to how it was before."* (Daniela)

*"Yes, in the past, everything ... in the past you used to see him always active, he would socialise and involve himself in everything, he would go around, as proud as a king, but then this [the disease] struck him."* (Anne)

Participants stated that living with a relative having a SMI poses problems which are not transient in nature, due to changes throughout the course of the illness. Consequently, participants perceived that they could never lead a 'normal' life and often searched for a meaning to their situation.

*"Sometimes I get angry, honestly, I get angry and ask why. But why did this happen to me?"* (Daniela)

Furthermore, caregivers who were parent grieved at lost expectations they held for their ill son or daughter.

*"... this week I was thinking about my son and I was saying to myself 'Were he not depressed, he would be married by now.'" (Anne)*

Male caregivers expressed more negative emotions towards caring for a person with mental illness in comparison to their female counterparts. They recurrently stated that they were facing difficulties associated with their relatives' behaviour and perceived being held accountable by health professionals when there was no improvement in their relative's mental health state. The following excerpt demonstrates the frustration experienced by Steve.

*"She [person with mental illness] wouldn't be aware of what she is doing, and it is of no use getting angry ... but it's only natural to get angry and sometimes I get furious and start swearing, that's how it goes, you know."*

Conversely, the female caregivers blamed themselves for triggering certain behavioural responses in their relative, as exemplified in Joyce's quote.

*"Honestly, when I'm tired, I get anxious and I snap at her, and she senses how I feel and retaliates back in an odd manner. That's when she alarms me, because I ask myself 'Why does she act like this?' Then I say to myself that I must have been the cause, I triggered her behaviour."*

Participants also explained how the stigma related to mental illness caused them much suffering. In fact, Joe described feeling hurt at seeing a family member suffer due to the stigma of mental illness at his workplace.

*"Once he [relative with mental illness] was treated at the psychiatric hospital ... on returning to work his colleagues thought he would do something irrational and they were scared that he would commit suicide."*

Moreover, two family caregivers reported that their relatives were frequently ridiculed and watched with curiosity.

*"If we go somewhere, they will just stare at him because he moves his leg or arm like this. My son is physically not the same as he used to be. Even the fact that saliva drips from his mouth, it really hurts me when people laugh at him. I'm aware of their behaviour but he doesn't mind, unlike me."* (Daniela)

In conclusion, all family caregivers expressed some type of emotional turmoil, as demonstrated by Karl who, however, explained what gives him the will to live.

*"... because sometimes that's what keeps me alive, because sometimes I feel like committing suicide, but those kids come to my mind [pointing towards his three grandchildren]."*

### 3.2 Increased responsibility

Participants who were parents worried about who would take over their role in the future and how their relative would cope without their assistance. Parents were strongly aware that providing care to a relative with a severe mental illness took up a substantial amount of their own time and energy. They also considered the siblings of a person with a SMI as having their own personal needs and life challenges. For this reason, they felt that it was unfair to impose such a responsibility on them. They viewed their own responsibility to provide care as an obligation.

*"It affects me in the sense that I am unable to relax, that I neglect my personal needs and that if she needs anything, she gets priority even if it means sacrificing my own needs to satisfy hers."* (Joyce)

Furthermore, whilst Anne was appreciative of the enormous support and help that she received from her children in providing care, Steve described his frustration at having to care for an ill relative on his own, as demonstrated in the following excerpt.

*"Some of them [other siblings] work, some own shops, some are married and have to take care of their homes, therefore they have a lot of responsibility and so I have to carry the burden all by myself."*

Participants described their role in providing complete care to their relative, such as preparing food, shopping, cleaning, providing transportation and accompanying them to appointments. Steve described the role change that happened in his life as follows.

*"Before she got ill, I used to go to work, and she prepared things for me, for example the clothes, the uniforms, and once I was back home she used to prepare something for dinner, nothing elaborate ... Nowadays, I do everything myself. I never knew how to do any house chores but then I had to learn to do everything."*

Furthermore, the caregivers expressed satisfaction that symptoms associated with the SMI had stabilised and were well-controlled by treatment. Yet, they were concerned regarding various side effects related to their treatment. As expressed by Karl:

*"She's a vegetable, lethargic ... when she has to walk, she does so without any urgency and I think it is the medication she's on because she wasn't like this when she was not depressed. She used to run, not walk. But now ..."*

Karl continued to describe the need to continually supervise the ill relative so as to ensure that she does not harm herself.

*"Sometimes, she has even left the key inserted inside the key-hole of the front door. It has become commonplace for her to be absent-minded, you can't trust her to stay unattended. For instance, she could very easily switch on the oven and then go to sleep."*

### 3.3 Toll on Physical Health of Caregiver

The majority of caregivers expressed their concern at the fact that although their ill relative was capable of carrying out basic activities of daily living, s/he still relied heavily on the caregiver's assistance. This dependency was mainly attributed to the relative with a SMI demonstrating a lack of willingness to do work. Furthermore, as described by Daniela, the caregiver gets accustomed to this behaviour after a period of time and accepts it. However, the constant stress and strain of caregiving is likely to have an adverse impact on caregivers' health, as described by Anne:

*"I am feeling more and more tired. In the evenings, I have to go to bed earlier to rest because I do need to rest, one really needs to ... , even if one was made of steel, even if you don't have so much to worry about, let alone with all my problems."*

Steve expressed similar concerns.

*"She has honestly got me miserable, I never know where I stand with her and I suffer from heartburn on a daily basis caused by the anxiety I experience."*

### 3.4 Change in Lifestyle

All the participants elaborated on how their lifestyle was affected. Two participants described social restrictions and feelings of stress, as demonstrated by Kim's response.

*"I go out but I get bored. When I receive a call, I tense up thinking that something has happened to my son...last time, I went out to play bingo, my youngest son was asleep, and instead of switching off the oven, I left it on. Thank God a thought passed my mind and I returned home because I might have killed my son and burnt the house down."*

Furthermore, some participants felt that they were only able to relax when their ill relative was being supervised, as exemplified by Joyce:

*"I try to keep myself active by going for a walk or an outing. I try to rest. However, to be honest, I only relax when there's someone else to care for her. That's the only way to relax and feel better."*

Other participants explained that disruption of life plans was also common, with some having had to leave their job, with the consequent effect of this on their standard of living.

*"...in the past, when I used to work, I never bothered when it came to spending. I used to tell her 'Go now and do the shopping and do not worry at all', because I earned enough money, but then she got ill and things changed. I couldn't keep my job. Nowadays, I have to be very careful on how I spend."* (Steve)

In fact, financial strain was an issue frequently mentioned by caregivers, even when the relative was not living in the same household. Reportedly, it was caused by the relatively poor financial situation of the ill relative due to unemployment, as explained by Steve:

*"...the benefits she receives do not always cover her needs. There are instances when she goes for months and doesn't require any financial help, however then comes a month when she needs frequent visits to the doctor. Many times I take meals over to her ... that's all out of my own pocket. I don't ask her to pay."*

## 4 Discussion

As deinstitutionalisation has gained momentum, increasing numbers of researchers have focused their research on the experiences of persons with a mental illness and their caregivers (Maurin & Boyd, 1990). To the authors' knowledge, no study has explored the lived experiences of Maltese caregivers who, along with their ill relative, were both receiving support from the community outreach team. The present study shows that providing care to a person with a SMI has an impact on the life of the caregiver. This impact can be categorised into experiencing a range of negative emotions, suffering a toll on one's physical health, feeling the need to make lifestyle changes and assuming an even greater amount of responsibility than before. These experiences may arise due to the increased needs of persons with SMI for day-to-day care and supervision (Chang & Horrocks, 2005). However, an additional contributing factor could be the experience of financial hardships (due to loss of income or increased health-related expenditure), as cited by participants in this study.

Moreover, those caregivers who were parents expressed concern on who would eventually replace them in providing care and how their ill relative would cope without their assistance. They expressed their appreciation for the support received from siblings and stated that this support helped them cope with the situation. Caregivers who were parents also expressed preoccupation with shifting the responsibility of care from themselves onto the ill relatives' siblings, as the latter had their own problems and commitments. These interesting dynamics within the family structure may represent the role of the family in Southern European countries as a network of micro-solidarity as well as in assisting coping (Moreno, 2002). In one case, a sibling (who lived on his own) expressed resentment at the fact that he was left alone to

care for his ill relative. The onus of care was placed on him as he was perceived to have fewer responsibilities and commitments than his other siblings. Consequently, it is important that family caregivers are made aware of a number of entities in Malta that offer long-term residential care for individuals having a SMI. For instance, one finds community homes and rehabilitation facilities that make use of care worker services provided by the local psychiatric hospital and/or non-governmental organisations. The question of availability of enough resources in this regard prevails, and the need for additional support as identified by studies such as the present one are indicated. Further research that explores family dynamics in caring for persons with a mental illness within a local context is required.

In the present study, the experiences of caregivers seemed to differ by gender. For instance, female participants tended to resort more to self-blame, attributing their actions as triggers for behavioural problems in their ill relative. This could be due to experiencing greater psychological distress, which has been associated with having negative thoughts and interpreting experiences in a negative manner (Burger, 1997).

Burnout was reported by all caregivers living with an ill relative, irrespective of their diagnostic group. Furthermore, caregivers expressed feeling a greater subjective burden with the patients' loss of functionality. The latter may have affected the caregivers due to their involvement in the day-to-day care of the ill relative, with many family caregivers reported to have to give up/decrease social activities (Samele & Manning, 2000), while others may take time off from paid work or may decide not to work full-time. Thus, caregivers may perceive that they are kept from self-actualising and developing their full potential due to their caregiving role (Ogilvie, Morant & Goodwin, 2005).

In this study, participants also described how stigma related to mental illness denied their relatives full integration into the community. Furthermore, due to stigma, situations of social exclusion, loss of friends and reduction of job opportunities were also reported. In fact, patient unemployment was recognised as the main factor that contributed to the caregivers' financial strain, even when the ill relative was not living in the same household. Other studies (e.g. Seloilwe, 2006) have also documented that caregivers experience the stigma of mental illness. Effective anti-stigma interventions are needed to empower caregivers and the person with mental illness to challenge both self-stigmatisation and discriminatory behaviour, and to target attitudes which are not conducive to social integration in the community (Buizza et al., 2007).

## 5 Strengths and Limitations

A limitation of the present study was that participants were all in the mid- or late adulthood phase (being 61 years and older). However, caregivers of persons with severe mental illnesses can be of various ages. Thus, there is the need to explore the experiences of family caregivers falling under other age categories.

The study has a number of strengths which include a) maintaining an audit trail throughout the process of analysis b) presenting excerpts from the interview transcripts to strengthen the reader's understanding regarding the process of interpretation c) conducting interviews by the same researcher to ensure consistency d) validating the analysis conducted by the first author by two other researchers and e) maintaining a reflexive stance throughout the study due to the professional roles of the researchers.

## 6 Recommendations

The role of the mental health worker is of importance in providing care and support not only to the ill relative, but also to other family members such as caregivers. This study also contributes to the extant literature, by demonstrating that support

provided should also target caregivers whether they live in the same residence as the ill relative or not. Care interventions can be conducted at an individual level and through the development of programmes which provide information regarding the illness, treatment, aspects of care, support services available and how to access them. The role of the caregiver in such an intervention should not be that of a passive recipient of information, but rather an active one, where personal experiences and the uniqueness of each caregiver's situation are acknowledged. Formulated interventions and care plans should then target the unique needs specific to each patient - carer dyad. In this way, one may reduce feelings of burden in caregivers while promoting personal growth.

## 7 Conclusion

Due to deinstitutionalisation, society and the health care system depend on the participation of families in assuming health care responsibilities of ill relatives. At the same time, however, they often "fall short of providing family caregivers with the recognition and support they need and often fail to acknowledge and make best use of the expertise family caregivers develop through their ongoing experience" (Jeon & Madjar, 1998, p.705). In fact, this study has demonstrated that family caregivers experienced the burden of care, irrespective of whether their mentally ill relative lived with them or not. Consequently, interventions that target the unique needs of these caregivers within a community setting are required.

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