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<th>Title</th>
<th>Family carers: lived experience of caring for relatives with an SMI</th>
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<tr>
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Key Points:

- The family caregivers of relatives with an ongoing mental illness face many challenges.
- When their relative first becomes ill, family caregivers often lack an understanding of mental illness and need sufficient information from staff. (Clarify)
- Family carers can feel excluded by health care professionals who decline to share information with them when maintaining patient confidentiality.
- Support groups play an important role in helping family carers cope, especially in the early phase of their relative’s illness.

Abstract

This study explored family caregivers’ lived experience of caring for a relative with an ongoing mental illness. An interpretative phenomenological approach (IPA) was adopted. Participants (n=8) were self selecting and members of SHINE (a voluntary Irish organisation supporting persons with mental illness and their families). Three super-ordinate themes were interpreted from the interview data. The first theme ‘nobody told me this was the way it is’ represents participants’ experiences of not understanding what was happening to their relative and what they should do when their relative was first diagnosed. The second theme, ‘feeling excluded’, represents the participants’ sense of exclusion. For some, the reason for this exclusion was because of the confidentiality embedded in the Mental Health Act. The final theme, ‘you don’t feel judged’ represents the importance of the support group to participants, especially at the beginning when their relative was first diagnosed. The study findings illustrate the importance of education for relatives, and the important contribution support groups play in providing support and education.
Introduction

Global de-institutionalisation of psychiatric care has been evident for sixty years (Hamden et al, 2011). However, this move to community oriented care has resulted in an increasing number of families assuming the role of caregiver to relatives with severe and persistent mental illness (SPMI). Indeed, modern healthcare is largely dependent upon informal carers to carry the psychosocial burden of care (Clarke et al, 2006), and families and friends of individuals with mental health difficulties are central to the treatment and rehabilitation process (Department of Health, 2006). However, problems faced by family caregivers are an international concern (Rowe, 2012). The role of carer is stressful and relatives can be challenged by the stigma attached to caring for relatives with a serious persistent mental illness (Chang and Horrocks, 2006), with many employing avoidance strategies to cope (Kartalova-O’Doherty and Doherty, 2008).

Relatives can feel alone and struggle to make sense and maintain normality in their lives (Jönsson et al, 2011). They can feel isolated from their communities (Kartalova-O'Doherty et al, 2006) and grieve the loss of the person they once knew (Champlin, 2009). In addition, these carers are at greater risk of psychiatric morbidity and stress related illnesses than the rest of the population (Yee and Schulz, 2000; Provencheher et al, 2003), and suffer from considerable burden as a result of their role (Aadil et al, 2010). Nurses therefore, need to ensure that relatives are cared for within a person-centred approach (McCormack, 2004). Moreover, a person-centred approach can evolve to promote carer empowerment by promoting mutual understanding in the ‘triad’ of care (i.e. the triad of person with a mental illness/carer/professional) where there is mutual exchange of knowledge and experience (Nolan et al, 2002).

Methods

This study aimed to explore and describe the lived experiences of relatives supporting an individual with ongoing mental illness.
This study adopted Interpretative Phenomenological Analysis (IPA) (Smith et al, 2009). IPA is both phenomenological and interpretive and central to this approach is the individual’s personal perception of an event. Illuminating the experience of relatives acknowledges what it means to be a person in that situation and ‘gives voice’ to the way a person interprets their experience.

In addition, the interpretive element of IPA’s ‘double hermeneutics’ acknowledges the researcher’s attempt to make sense of the experience relayed by the study participants (Smith et al, 2009, p. 3). Importantly, with IPA, the researcher’s pre-understandings are viewed as ‘…necessary precondition for making sense of another person’s experience’ (Willig, 2008, p. 69). However, researchers using IPA are advised to ‘park or bracket...pre-existing concerns’ to allow them focus on the study participants’ accounts of their lived experience (Smith et al. 2009, p. 64). Significantly, IPA is also idiographic in that the researcher must firstly totally immerse themselves in their reading of each study participant’s transcript before later integrating analysis of all the study transcripts (Willig 2008).

Participants and recruitment

‘Less is more’ when considering the number of participants with IPA (Reid et al., 2005), because this fits with the ‘idiographic commitment’ of IPA (Hefferon and Gil-Rodriguez, 2011, p.757). Smith et al (2009) recommends between five and 10 participants when using IPA as they argue that reduced number of participants allows for a richer depth of analysis that might be inhibited with a larger sample. Participants (n=8) were self selecting and members of SHINE (a voluntary Irish organisation supporting persons with mental illness and their families). The SHINE National Office facilitated recruitment and distributed information leaflets in one regional area. The information outlined the purpose of the study and asked those interested to contact the researchers if they wished to be interviewed. Seven women and one man contacted the researchers and were subsequently interviewed. All participants except one were aged over 50 years (Table 1).

Interviews were conducted on mental premises across the region that were geographical convenient and acceptable to participants. These mental health premises were not those that participants’ relatives attended for services. Participants were asked about their caring
experiencing focusing on the following themes; to describe their experiences of providing care and support to their relative and also asked to describe what they found difficult and what support services helped them. All interviews were audio taped and transcribed verbatim.

Ethical approval was granted from the Regional University’s research ethics committee. Informed written consent was obtained from each participant prior to being interviewed. In order to protect confidentiality, each participant was given a pseudonym.

Data analysis was analysed following the principles for analysing phenomenological data proposed by Smith et al (2009). All three authors verified the findings and following discussion, reached agreement on super-ordinate themes.

Findings

Three super-ordinate themes were interpreted from the interview data; i.e. ‘nobody told me this was the way it is’; ‘feeling excluded’; and ‘you don’t feel judged’.

Nobody told me this was the way it is

This super-ordinate theme represents participants’ experiences of not understanding what was happening to their relative and what they should do when their relative was first diagnosed. This was due to inconsistence of information provision and explanation from staff of what was happening to their relative and what to expect.

Jane. “I thought when my son became unwell first, after his first hospitalisation, I actually, I was naive, I thought we’d be all brought in, the whole family like, and just kind of to work through whatever issues is going on, but that didn’t happen.”

Lucy. “When he [son] got the illness, I could find no support there, and nobody told me, nobody brought me in the hospital and said “this is the way it is” which is very wrong really, it should be all explained to you about the illness, because it isn’t easy living with somebody with that illness, no matter how good they are”.

Participants also talked about the stress they experienced as they negotiated living in their new previously unknown world.

Molly. “I’ll tell you first that my daughter has, was diagnosed in the past two years, and prior to this I really had no personal experience of mental illness – would have had known a little bit. And I suppose the initial day when she was admitted to
hospital, it was very traumatic, the most traumatic experience I’ve ever had in my life – I’ve had other illnesses, deaths in the family, traumatic occasions have occurred, but there was nothing to compare with the shock and the stress of having to deal with it”.

Trevor. “I found it very hard at this start to get ***[wife], to get her to go to a psychologist at the start. She found a lot of the trouble, that it was me that had the problem! And she’d be alright if I didn’t make her go to these doctors, and she wouldn’t be on medication if I didn’t make her go to the doctors, so! I probably feel there should be more time spent with people getting them to understand, because to this day I don’t think *** understands fully her own illness”.

Alice: “You’re kind of treading on eggshells, you know, and you’re watching what you say, and thinking what you’re doing, and that, do you know, it’s difficult”.

Feelings of loss were also expressed by participants.

Jane: “Well I know he has no friends, we’re the only people in his life. And I don’t mind, I’d do absolutely anything for him, but I’m aware that he’s aware of that, do you know what I mean, and that’s not good either…you do grieve, and you do kind of, you know, you’d like things to be better”.

Helen: “It’s not the life I would have expected for them, but once they’re happy I don’t mind, yea we’re good to them, we support them all the time”.

**Feeling excluded**

A sense of feeling excluded pervaded the participants’ experiences. For some, the reason for this exclusion was because of the confidentiality embedded in the Mental Health Act (Government of Ireland 2001).

Molly: “…no person could speak to us! Now the Mental Health Act was quoted as being the reason, but I think this was taken to extremes, because you’re voluntary, you’re an adult, you have no part to play in your relative being in care…It’s just crazy. I just feel that the whole thing was crazy. And such a little thing would have done, somebody just to speak to you!”

Jane: “Well it is very disempowering, when he was unwell, he was laughing to himself and talking to himself, but trying access help is impossible, because of all, legislation…and the Psychiatrist didn’t want to know, it was her way or no way, you know, it was either the Depot injection or, you know, or, yea, she wouldn’t listen”.
The stigma surrounding mental illness added to the sense of isolation and exclusion felt by participants.

Trevor: “And I know there is a lot being done the last couple of years, but I still think we have mountains to climb in all of that area. And even at work, this time, I wouldn’t be publically saying that my wife is sick, even though I know everyone in the place knows there’s something wrong”.

Lucy: “…unless we talk about it, it’s going to be a stigma forever. I know myself if you say to somebody “oh my son is schizophrenic” they nearly lose their life like, like they’re nearly backing back from you, like as if it is some kind of a plague. But, it’s like all mental illness, we have to bring it out…”

Alice: “Because the thing with mental illness, do you know, if it was a physical illness you had, or someone had, you could go to someone else in a similar position and say “oh well what did you do like when, you know, when there was this wrong with your relative?” But mental illness, people aren’t inclined to talk about it, so there definitely still is stigma attached to it. So do you know that confines you as well”.

You don’t feel judged
Six participants talked about the importance to support groups to them, especially at the beginning when their relative was first diagnosed. Meeting others in the support group also helped some participants adjust their perspective.

Molly: “The group, its held locally, and it’s every month, and there is a nurse who is the team leader, and she facilitates the group, and we are all, it’s all very private, and you’re allowed to speak, and you can say, no matter what it is that’s on your mind, you can speak it, and you feel you are speaking to other people who know where you’re coming from, and you don’t feel judged”.

Jane: “…at the beginning, how that [support group] helped me at the beginning, you knew you weren’t alone, because you wouldn’t have known too many families with people that had schizophrenia, where with depression it is more acceptable, because it is awful hard to get your own head around that at the beginning, you know. So like some behaviours, you know, and, so, yea, it did help. But I know from the other group members, they really look forward to it now every month”.

Lucy: But then I was told about this meeting that was on [support group], where I live, and there was a wonderful social worker, I think she is doing it voluntary,
leading this meeting, and a group of us used to go there, and the women and the men there gave me great courage, they talked about their children, which I thought “nobody has this illness”.

Sara: “…you come away [from meeting] feeling “well I think I’m bad, but there are people an awful lot worse off”. Which is, you know, while of course you don’t wish anything on anyone else, but it puts things in perspective really”.

Discussion

The stress experienced by relatives in this study echo those reported by McAuliffe et al (2014) who describe ‘the psychological tsunami’ caused by a diagnosis of schizophrenia. However, a finding reported here, not reported by McAuliffe et al (2014) is participants’ sense of feeling excluded and their viewpoint that legislation and patient confidentiality contributed to this sense of exclusion.

Mental health legislation is necessary to protect the rights of people with mental health issues. Ireland’s Mental Health Act (Government of Ireland 2001) was fully implemented in 2006 with the intention of bringing Irish legislation more in line with international standards. Study participants viewed this aspect of the Act as an obstacle for their inclusion in the care process. Nevertheless, the Act has made positive provision to reduce this distress with the introduction of the role of the Authorised Officer as someone independent of the family and Garda who can make an application for admission to hospital. Besides this, the Act makes little other provision for family involvement focusing on the needs and right of confidentially of the service users. Ireland’s Mental Health Act (Government of Ireland, 2001) provides limited provision for the role of family involvement in a relative’s mental health treatment other than a role in making an application for admission. Internationally, gaps remain between the views and rights of carers, education and knowledge of the act for all stakeholders, including carers (Latif and Malik, 2012). This gap in the Mental Health Act in the UK is also reported (Marriott et al, 2010). Currently best practice advocates for collaborative and partnership working between all stakeholders working within legislation. (Worthington et al, 2013)

A key tension that exists between carers, service users and professionals relates to the sharing information and confidentiality (Pinfold et al, 2004), and carers report that confidentiality is used as a reason for professionals not to share information, despite government initiatives that recognize the importance of the caring role (Rethink, 2003). Evidence suggests that details of
treatments, symptoms and long-term care are frequently not shared with carers (Pinfold et al, 2004). However, carers may also be reluctant to share information with professionals in fear of breaking family loyalty, the reprisals of close relations, and fear of hospital admission for their relative (Rapaport, 2002; Pinfold et al, 2004).

In the face of perceived communication obstacles, it is vital that staff are “carer aware” and receive training in carer engagement strategies (Worthington et al, 2013). The attitude of psychiatric nurses towards involvement of families in care is central to the quality of interventions families will be offered (Sveinbjarnardottir et al, 2011). The different perceptions of health professionals to families’ care giving role are highlighted by Small et al. (2010) who suggest that health professionals should endeavour to engage with carers rather than being critical of them for not conforming to professional assumptions. Short therapeutic conversation intervention from nurses provides family members with a feeling of being supported both emotionally and cognitively (Sveinbjarnardottir et al, 2013). Other simple measures such as building a working alliance with families/carers also promote two-way exchange of information (Radcliffe et al, 2012). Participants in our study expressed a need for more education; there is also considerable evidence for offering family intervention in the order of education, training, consultation and information (Froggatt et al, 2008). Such interventions are recommended in NICE guidelines where supporting families is acknowledged as impacting positively in improving efficacy in relapse for service users with a diagnosis of schizophrenia (NICE, 2009).

Being a carer can raise difficult personal issues about duty, responsibility, adequacy and guilt (Oyebode, 2005), and many of the issues raised for caregivers of a relative with dementia are also of relevance to caregivers of relatives with a mental illness (Oyebode, 2003). Carer burden is widely reported in a European context with national difference in healthcare provision cited as a key factor in determining the extent to which families are affected (Rowe, 2012). Moreover, it is important to acknowledge that whilst all but one of respondents were female, no significant variance between male and female carers has been reported by Kartalova-O’Doherty et al (2008). Support groups can help ameliorate carer burden, and are an essential point of knowledge transfer and central in promoting recovery (Scottish Recovery Network, 2009).
A sense of loss among the study participants is also evident. Grief is an aspect of the caring process (Magliano et al. 2005). This may be experienced as grief for the loss of the person’s former personality, achievements and contributions, as well as the loss of family lifestyle. This grief can also lead to unconscious hostility and anger (Ostman et al. 2004; Magliano et al. 2005).

The stigma surrounding mental illness was also a study finding. Families experience stigma through their association with their relatives. Families assume major roles in supporting relatives with mental illness and face enough challenges and barriers in this role; stigma should not be an additional barrier (Larson & Corrigan 2008).

In conclusion, this study’s findings highlight the sense of isolation felt by carers, especially when their relative first becomes ill. There is a need therefore for nurses to remain cognisant of the importance of a relationship-centred approach (Nolan et al, 2002) when communicating with relatives. Nurses also need to provide standardised evidence based information to carers. Such an approach promotes mutual exchange of knowledge between carer, their relative and mental health nurses, and may relieve carers’ sense of exclusion.

Acknowledgements
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References


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Table 1: Participants’ demographic information

<table>
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<tr>
<th>Participant’s relationship to relative.</th>
<th>Participants Age Category</th>
<th>Length of time caring for relative</th>
<th>Diagnosis given to relative</th>
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<td>Mother (of daughter)</td>
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<td>Bi-Polar</td>
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