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Siblings of individuals with severe mental illness

Abstract:

Purpose – The importance of providing information, support and interventions for family members and carers of people who have severe mental illness (SMI) has garnered increasing attention in recent years. However, research to date has primarily focused on parents and carers; few studies have investigated the experiences of siblings of individuals who have SMI.

Design/ methodology/ approach – A literature review was undertaken to summarise the empirical data regarding 1) the experiences and needs of siblings, and 2) their potential contribution to supporting their brother or sister experiencing mental illness during their recovery journey.

Findings - Siblings often make significant contributions in their brother's / sister's care and social and emotional wellbeing, and such support can positively shape the recovery trajectory. Siblings remain largely invisible in mental health services. This review finds that siblings need information and support for two reasons: 1) to maintain their own wellbeing and 2) to be able to best support their sibling with SMI and family as a whole. Implications for clinical practice, workforce development and research are identified and discussed.

Originality/ value – Sibling-specific needs and experiences are poorly understood. This is the first article to consider how best siblings' needs can be identified and met, and the implications for health care providers.

Keywords (up to 10 keywords): siblings, recovery, family, carers, psychosis, schizophrenia, severe mental illness

Article classification: General review

Introduction

While mental health services have embraced the concept of family-inclusive practice for several decades, this has largely involved a focus on parents - as both providers and potential recipients of care and support (e.g. DH, 2010). Conversely, there has been a paucity of attention given to the needs and experiences of siblings of people who have severe mental illness (SMI): they have remained largely invisible within statutory health and social care organisations. This is somewhat concerning given that ninety percent of the population have at least one sibling (Buist et al., 2013; Milevsky, 2011), and sibling relationships often outlast friendships, and personal and professional relationships. People who experience SMI often maintain limited social networks during the prodromal, acute and recovery phases of their illness (Rethink, 2006; DH, 2010); and hence, their siblings may be the only peers of a similar age they maintain regular contact with; and they may provide ongoing practical, social and emotional support (Sin et al., 2012). Whether siblings should be in receipt of information, services and support – as part of a ‘family unit’ or as individuals in their own right – has not been adequately investigated, and this raises philosophical and ethical issues, as well as dilemmas for practitioners and service providers.

Overview of this paper

This paper provides a review of the empirical literature and current thinking about siblings who have a brother or sister affected by SMI, in particular psychosis. This paper considers sibling perspectives: What are their experiences? Do they want or need support? Are their needs distinct from or dependent on, the family unit? Considerations for mental health practitioners are also highlighted: Should practitioners routinely ask about siblings and consider them within the assessment process, e.g. as a family member or potential carer? If so, how best can mental health practitioners support and work collaboratively with siblings?

Siblings’ experience

The onset of SMI, for example schizophrenia and psychosis, tends to occur around late adolescence and early adulthood (Buchanan & Carpenter, 2005). The impact of SMI is wide-ranging: affecting the person themselves across social, occupational and daily functioning, as well as others around them (NICE, 2014). The impact of mental illness on the family unit as a whole, and family members individually can be short-term (such as coping with acute onset or inpatient admission), as well as pervasive and enduring (such as providing long-

term care) (Saunders, 2003). Increasingly, the evidence suggests that siblings are also often affected by their brother's or sister's illness experiences (Sin et al., 2013; Friedrich et al., 2008). When a person becomes unwell, their brother or sister is not only affected by the changes the symptoms pose to the sibling relationship, but also the impact these cause for different family members and the family unit as a whole.

Similar to parents, who often act as key informal carers for the person with SMI, siblings often experience a range of emotions in response to their brother/ sister's illness experience. Changes can occur in familial relationships, and caring demands placed on them can increase (Smith et al, 2009). Seeing a person becoming unwell and displaying behaviours such as paranoia and suspiciousness, can prove highly distressing for the siblings (Sin et al, 2012). Challenging behaviour such as physical aggression and violence has been identified by siblings to be the most difficult aspect to deal with (Friedrich et al 2008; Greenberg et al, 1997). Siblings also commonly describe worries of being judged and stigmatised because of their siblings' mental illness experience, a phenomenon commonly encountered by family carers (DH, 2002). Consequently, they often choose not to share information about their sibling's SMI and the impact this has, with teachers, workplace colleagues or even with close friends (Sin et al., 2012). Siblings describe worries about the increased risk of mental illness for themselves and their children due to genetic risk (Sin et al., 2012).

SMI within the families often brings changes in family dynamics and a shift in family roles (Seeman, 2013). For instance, parents may be less supportive as they provide more support to their child with SMI, and whereas once a sibling may have been the receiver of support they may now be the provider of support for their sibling or others in the family (Griffiths and Sin, 2013). Feelings of grief and loss are common amongst siblings due to a perceived loss of a brother or sister they used to know, and the interaction, inspiration and support they used to provide (Patterson et al., 2002). For some, these changes also lead to feelings of 'survival guilt' - siblings may feel guilty for not being the one who is ill and consequently place themselves under extra pressure to achieve in life so to compensate for perceived lost opportunities for their brother/ sister (Sin, 2013; Angell et al., 2012). Very often, siblings describe experiencing pressure, to help care for their brother/ sister from a young age (Angell et al., 2012; Greenberg et al., 1999). An implication is that these factors may exacerbate stress in siblings, and contribute to or heighten vulnerability to a range of health issues, such as depression or sleep disturbance (Greenberg et al., 1997; Ma et al., 2014).

Contrary to the literature focusing on the negatives of siblings' experiences, there is also a small but growing attention on resilience factors (Seeman, 2013). Many siblings consider that their brother/ sister's illness has strengthened their sibling bond and family cohesion, when they have reflected on their experience (e.g. two or three year after the initial onset of psychosis) (Sin et al., 2012). Individually, some siblings perceive themselves as becoming a "better" person: that they are more understanding, empathetic and sensitive, as a result of their experiences. Many siblings have also described feeling proud and gaining inspiration from their brother/ sister and their battle to recover (Angell et al., 2012).

Siblings' contribution to their brother / sister's recovery and care

For individuals who experience SMI, the sibling relationship can be particularly influential during their illness experience. Having a supportive sibling has been associated with a better quality of life for those with psychosis (Smith et al., 2007). This may be due to siblings being pivotal in initiating and maintaining social overtures and social opportunities (e.g. going out, family gathering, and visiting their brother/ sister) and providing emotional support (e.g. chatting, and sharing 'ups and downs') (Sin et al., 2012). In terms of long-term prognosis, having supportive siblings can be beneficial for facilitating a positive recovery trajectory (Smith et al., 2007).

Making sense of and coping with mental illness

To date, most research studies with siblings of individuals with SMI have been conducted with siblings in their 40s and 50s after they have taken over the key caring role from their parents (e.g. Greenberg et al., 1997; Landeen et al., 1992). A common theme in these studies reflects perceived pressure imposed on siblings (e.g. from parents) to take on the caring role and the burden of care for their brother or sister with SMI. Research has also identified that the extent of the siblings' involvement in their brother or sister's care later on in their lives is often determined by their relationship in late teenage years, i.e. if the sibling relationship is close then, siblings are more likely to remain close for the rest of their lives regardless of geographical distance and personal circumstances (Smith et al., 2007; Greenberg et al., 1999). At the same time, the extent to which a sibling feels ready to support their brother or sister also relies on their understanding of the illness at first onset (Greenberg et al, 1999; Smith et al, 2007).

Without information about the illness and ways to care for common acute symptoms and secondary challenges, siblings may struggle to understand the diverse experiences inherent to SMI, which may lead to withdrawal and detachment (Sin et al., 2012; Seeman, 2013). Siblings also commonly find negative symptoms of psychosis such as losing motivation and apathy, which often are much more long-standing than acute psychotic symptoms, mystifying and frustrating (Friedrich et al., 2008; Smith et al., 2009). Siblings who do not understand such symptoms and attribute them to their brother or sister) rather than their illness, may appear less empathetic and subsequently less likely to be involved in their care (Seeman, 2013). While emotional and / or physical detachment may provide a degree of emotional or cognitive respite in the short-term, the impact on the sibling relationship and the siblings' sense of belonging can be negative (Smith et al, 2009).

Support for siblings

Siblings are not typically regarded as carers and seldom access carer's services (Rethink, 2006; Sin et al., 2012; Friedrich et al., 2008). Nonetheless, a consistent theme emerging from research investigating siblings' needs concerns information about the illness condition and ways to offer support (e.g. Friedrich et al., 2008; Sin et al., 2012; Angell et al., 2012). Information and support may mediate how siblings perceive the stressors (for instance, having better understanding of psychosis and resources available may help siblings feel less frightened or worried) as well as enhancing their repertoire of coping skills (such as better problem-solving skills in dealing with caring issues). Better-informed siblings are more likely to be involved in their brother/ sister's care and feel more empowered to do so (Lukens et al, 2002; 2004; Friedrich et al., 2008).

So perhaps mental health practitioners should consider how best to assess siblings' needs, and offer appropriate support and services accordingly. A significant proportion of services for siblings are run by non-governmental organisations (NGOs) and use innovative delivery formats and collaborative co-production models. Mental health practitioners need to be orientated with national and regional services available so as to be able to signpost siblings (Sin et al., 2013). Siblings' right to seek support, information and services should be acknowledged and respected, regardless of their brother/ sisters' or parents' opinion. The current status quo is that practitioners ask about the family composition of service users as part of routine comprehensive assessment. Once siblings are identified through the holistic

assessment process, the questions of whether they want information, support or services can be directed to them.

Mental health practitioners can encourage siblings to access services and prioritise their own wellbeing. To actualise a truly family-inclusive service and include siblings in routine service provision, practitioners need to consider involving siblings throughout all stages of care, from assessment through to interventions. While traditional workforce training may have been individually-focused, further training that promotes collaborative working with families and carers and adapts interventions to engage siblings should be considered (Smith et al 2009).

Good practice and service development examples

In the UK, the NICE guideline for psychosis and schizophrenia recommends two family-based interventions (NICE, 2014). One is psychoeducation – information-giving on the condition and treatment strategies - a psychosocial intervention that should be provided to family members including siblings. The other is family intervention (FI) for people who experience psychosis and their family members. FI is identified as particularly beneficial in reducing relapse and enhancing coping in the family units (NICE, 2014).

In routine clinical services, siblings' participation in FI is low (Smith et al., 2009; 2010). A number of obstacles have been identified, including clinicians' attitudes and awareness of siblings' needs and roles; siblings may not be top of the priority list amongst competing clinical demands such as caseload; and siblings' lack of awareness that they might be eligible to be involved in treatment (Sin et al., 2012). Suggestions to include siblings in family-inclusive service provisions and family-based interventions are made by Smith and colleagues in the field of early intervention in psychosis. To facilitate this they suggest providing interventions during out of office hours and at a convenient venue for the whole family, explicitly inviting siblings and valuing their participation (Smith et al., 2009, 2010). Only to a very limited extent have practitioners provided siblings with psychoeducation, however, siblings have been able to access psychoeducation and peer support online through resources such as the *E Sibling Project*, provision of an ehealth intervention (Sin et al., 2013).

Innovative partnership working between statutory and NGOs and coordinated care across primary, secondary and tertiary healthcare settings have potential to address siblings' needs in a dynamic and flexible manner (Lukens et al., 2004; Rethink, 2006). Whilst specialist mental health services may be the main care provider for individuals who have SMI, their siblings are more likely to seek support from primary care, NGOs, schools and youth-organisations (Sin et al., 2012; Rethink, 2006).

Awareness of siblings' needs has gained particular momentum with various charities and voluntary organisations over the last decade. The Canadian Mental Health Association has taken the lead to produce *A Sibling's Guide to Psychosis* for siblings (CMHA, 2012). In Australia, *Siblings Australia Inc.* is a unique national organisation, run by siblings, to provide support for brothers and sisters of people with special needs, including disability, chronic illness and mental health issues (Siblings Australia Inc., 2013). In the UK, several web-based resources have been set up and run by leading charities for siblings of people with SMI (Griffiths & Sin, 2013). These NGOs provide information and peer support via means of online forums and/or face-to-face groups for siblings. Mental health campaigns such as the Siblings Network run by *Rethink Mental Illness* have done much to raise awareness to siblings' contribution and needs across organisations (Griffiths and Sin, 2013).

Clinical implications

Enhanced identification and consideration of siblings' needs and experiences leads to several implications for clinical practice:

A comprehensive assessment process should always include asking about the person's family situation and social network including their siblings, potentially using a genogram: a diagrammatic representation of 'who is who in the family' (Butler, 2008). Developing a genogram together with the person who has SMI can be used as a process to gather personal information, find out about who are the key people in their life as well as to cultivate engagement (Milewski-Hertlein, 2001).

Once the family situation is known, such details may inform a systematic and collaborative formulation. Studies involving siblings of people with psychosis indicate that family-inclusive meetings with practitioners from early on may encourage engagement with the family unit

(Sin et al, 2012; Smith et al, 2009). Face to face meeting with mental health practitioners can provide an opportunity for family members including siblings to mention their views or concerns. Care planning can be approached from a multi-dimensional and family-inclusive manner in order to explore and address different but often interacting issues/ needs.

During provision of treatment, and subject to consent, family-based interventions can be optimised to include every person who is close to the individual with SMI. In some instances, practitioners could consider enlisting siblings as a therapeutic agent in their brother / sister's social and normalising activities. While it is important to let siblings know that support is available for them, it is equally crucial that siblings are given a choice in taking on the carer role or participating in their brother/ sister's treatment (Rethink, 2006).

Research implications

There is relatively little research about the experiences and needs of siblings, especially when they are young and before they take up a carer's role. Information and interventions specifically designed for siblings of people with mental illness are also lacking. Currently research evidence about family-based interventions – which have largely focused on parents, especially mothers in their (late) adulthood – is not systematically applied to siblings. It is unclear whether siblings' needs of and responses to such interventions are consistent with that of their parents. Whilst siblings may share many common adjustment and caring responses with parents, like grief and loss (Patterson et al., 2002), they may also have specific and unique needs that imply interventions targeting siblings may need to be modified and adapted. As many siblings may take on a carer role for their brother/ sister in the future, research is needed to explore what support is most appropriate to ease transition into the caring roles for siblings. Further research on interventions – offered flexibly - and targeting siblings, both as a support-agent for their brother/ sister, and in their own right, seems appropriate.

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