



MENTAL ILLNESS FELLOWSHIP of Australia Inc

Literature Review:

**The Experience and Support Needs of Adult Siblings
of People with Mental Illness**

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Executive Summary

Having a sibling with mental illness can potentially impact upon all relationships encompassing siblings, parents, spouses, children and friends. Many siblings speak of the strain placed on their spousal relationship due to a lack of understanding, resulting in both parties feeling isolated and with unmet needs [1, 2]. Having a sibling with mental illness can impact upon an individual's decision-making regarding family planning. Siblings identified that leisure activities were the activities greatest impacted upon as this life area was seen as less important to maintaining and often was viewed as less significant to other areas of living such as work and household maintenance.

Siblings may feel powerless and helpless with their sibling's situation however they are often the one to take charge when their sibling becomes unwell. Coping with changes in the individual's personality and behaviours is one of the greatest daily challenges voiced by siblings [3-6]. Communicating with a sibling who is experiencing disordered thoughts or delusional thinking is an area in which siblings identify as particularly difficult [1]. Communication difficulties can also make assisting with problem-solving challenging [7].

Siblings identify that the responsibility for caring for one's sibling exceeds beyond supporting their mental well-being. With each relapse, some siblings blame themselves for not being able to stop the decline in health that their sibling is experiencing. Many siblings provide assistance to their siblings with daily tasks in the form of instrumental support (household tasks, transportation, medical appointments) and emotional support. In addition to present day concerns identified by Landeen et al. [7], Smith, Greenberg and Seltzer [8] identified future concerns that siblings held for their loved ones. These included having adequate financial and transportation support, engagement in leisure and social activities, concerns regarding the progression of the illness and meeting medical needs, and the availability of future resources and emotional support. Some siblings identify that being separated from their sibling for a period of time would provide relief and time to re-energise.

Siblings often worry about the strain and stress that other family members, particularly parent primary caregivers, are placed under when a sibling is unwell [9]. Siblings experience a sense of guilt regarding witnessing parents under strain and feeling impotent to help. Communication between family members and differing opinions regarding the well-being of the sibling with mental illness often causes friction within families.

One of the greatest challenges siblings face are their own and their sibling's involvement with the mental health system. Many siblings feel their concerns are often not validated nor listened to by health professionals, often resulting in responses that are insensitive and uninformed regarding their needs [4, 10]. Siblings identify becoming disillusioned with a system that is meant to assist, and which instead further complicating their situation.

Parents and spouses are predominantly recognised as playing a caregiver role in the recovery of people with mental illness. Siblings appear to lack this recognition and as a result, experience difficulties with accessing sibling medical information due to confidentiality issues and lack of involvement in care planning regarding their sibling [4].

Siblings identify a range of benefits to having a sibling with mental illness. Literature revealed that not only does the process of living with a sibling who has mental illness contribute to one's personal development and growth but this also has positive ramifications and consequences on the nature and strength of all other life relationships.

Literature Review

Introduction

With the emergence of deinstitutionalisation, society has seen a move from hospital care to community support for the individual with mental illness. Along with community rehabilitation and support services, informal support networks have assisted in supporting the recovery of individuals with mental illness in realising their fullest potential and living well [11]. The most significant of these informal supports is the family unit in supporting the life goals of the individual.

Literature to date has focused on the role of the family in the caregiving, rehabilitation and recovery of people with mental illness [2-5]. Much of this literature has focused on the parental experience of having a child with mental illness and the subsequent effect on their lives and way of living [12-15]. Studies have also focused on the effect of mental illness on the family unit as whole as derived from the voices of parents. As a result, there has been a growth of family-oriented services including family psychoeducation and therapy. However, the role of other family members remains relatively underexplored. Parents and spouses most frequently comprise the primary caregiver role for an individual with mental illness, however siblings constitute the next generation of caregivers when the parent has passed away or is no longer able to provide care or when an individual does not have a spouse [16].

The sibling relationship is the longest in duration of any kinship in life [17]. It is typically characterised by mutual concern and support and affection for each other. Typically, sibling support fluctuates across the lifespan – childhood and adolescence sees the sibling bond at its closest and most intense [18]. This is followed by a waning of intensity and lessening of contact as the bond between siblings is superseded by relationships with spouses and the beginning of families. With the natural progression of life, adults age, spouses die or go their separate ways, children leave to begin their own independent lives, and hence the sibling bond becomes closer once again, however not reaching the intensity that it once was in childhood [18]. The need for instrumental and emotional support between siblings gains significance into adulthood and later years [19].

With siblings where one individual has a severe mental illness, support tends to be less egalitarian which sees the other sibling providing more of this support without it necessarily being reciprocated [19]. Siblings of people with mental illness experience greater objective and subjective burden than siblings of any other disability [4, 20, 21]. They are also more prone to experience ongoing sorrow, pain and loss than siblings of people with any other disability. The reasons for these differences in caring experiences between disabilities are numerous. The impact of the episodic nature of mental illness and associated uncharacteristic behaviours of the sibling with mental illness, the change in family and societal roles and the effect on one's own well-being, relationships, and life course has begun to be documented within sibling literature [11,14,16-20].

Search strategy

Relevant electronic databases were searched to identify existing literature on the experience and support needs of siblings of people with mental illness from 1990 to present day. The databases searched were AMED (Allied and Complementary Medicine), CINAHL (Nursing and Allied Health), Cochrane Database of Systematic Reviews, Cochrane Central Register of Controlled Trials, Cochrane Methodology Register, ACP Journal Club, DARE, CCTR, ERIC (Education), Inspec, Medline, Premedline, Oldmedline, Mental Measurements Yearbook, PsychINFO, PscBOOKS, Social Work Abstracts, Web of Knowledge and SAGE (Science and Geography Education). For each database, the following search terms were used to locate

articles: (sibling or sibling relations) AND (mental disorders OR psychiatric disorders OR mentally disabled persons OR mentally ill persons) AND (support OR experience). Different combinations of these keywords yielded various literature which were scanned for their relevance to the topic by reading the titles and abstracts. The reference lists of each article relating to the topic areas were screened for new, potential articles not located by the online databases. This process was continued until data saturation was reached where no new articles or information were appearing in the reference lists.

Qualitative studies as well as quantitative studies were included. Studies that focused on the experience of child siblings were excluded.

Trends in sibling involvement

Various factors have been identified as predicting the likelihood of a sibling's involvement in supporting another with mental illness. Sisters tend to be more involved in supporting siblings with mental illness than male siblings [20-22]. Lukens, Thorning and Lohrer [4] hypothesise that this is because females have a higher emotional awareness than men, are more inclined to express themselves more openly and hence are more likely to offer support to their siblings. As a result, sisters report greater subjective (emotional) burden than brothers.

Siblings who are older than the individual with mental illness are more likely to provide greater help [18]. However, younger siblings who provide support experience greater global subjective burden, stigma and fears relating to developing mental illness [22]. Unmarried and childless siblings are more likely to provide help, especially with instrumental activities (household tasks, transportation, medical appointments) [8, 16] and consequently report greater objective burden (strain of providing assistance with instrumental tasks) and subjective burden (emotional and psychological strain) [4].

One of the strongest determinants as to the degree of involvement a sibling has with an individual with mental illness is the quality and reciprocity of their relationship [16]. A close relationship in the teenage years, encourages a sibling to provide support in way of instrumental tasks later in life [8, 23]. Inversely, if a sibling had a reduced feeling of closeness with their sibling or had felt threatened or been exposed to violent behaviours from the individual with mental illness, then there is a tendency to provide limited support to one's sibling and ambivalence regarding one's caregiving duties in the future [24, 25]. In sibling relationships where each individual contributed to the relationship, and where the caregiver sibling felt personal gains from giving, future caregiving roles are more likely [8].

Siblings who had both parents passed away provide greater care than those who still had one or more parents living. Having no parents living predicts greater face-to-face contact, telephone contact and hence greater intimacy in sibling relationships [18]. Geographical distance also determines the likelihood of face-to-face contact of siblings and willingness to help the sibling with mental illness [18, 26]. A sibling who lived in closer proximity to their brother or sister is more willing to assist with instrumental tasks and spend time with their sibling.

The Sibling Experience

Emotional and psychological impact of having a sibling with mental illness

Siblings identify an abundance of emotions and thought processes resulting from the experience of having a sibling with mental illness. An overwhelming response from many siblings in studies is their perceived sense of lowered personal regard and sense of self due to being 'overshadowed' by their sibling's mental illness [1-3, 5, 6, 20, 21]. This lack of self-identity results in poor self-esteem and self-worth [2, 5].

Siblings articulate experiencing a gamut of emotions paralleling Kubler-Ross' Five Stages of Grief as identified by Riebschleger [10]. Siblings at first often experience denial as to their sibling's illness or often have to deal with their sibling or family members who do not accept illness diagnosis. Immense anger aimed at the illness and its devastating effects, their sibling, their family and life in general, engulf siblings and often resurface when their sibling episodically relapses [19, 24, 29]. Some siblings experience resentment against their sibling for taking their parent's time and causing familial disruption [9, 20]. Bargaining soon follows with siblings attempting to try out individual activities in order to 'cure' the situation they find themselves in [10]. Some siblings experience 'survivor's guilt' and blame themselves for eluding illness [3].

Some siblings find themselves experiencing situational depression, sometimes evolving into more serious mental health problems. Siblings identify grieving for the loss of their loved one whom they are uncertain will ever return [1, 2]. In turn, siblings speak of trying to adjust to living with this 'new person' with a different personality and behaviours and hence, trying to find one's own sense of self within the family again. Some siblings feel so greatly overwhelmed with the change in their sibling that they distance themselves from their loved one and their family, either physically or by introverting into themselves [1, 9]. Some siblings identify feeling a deep sense of guilt for not being supportive enough to their sibling. Shame caused by social stigma reduces social opportunities such as inviting people home and disclosing home situation with people [9]. Hopelessness and anguish are also experienced in response to the change in character of their loved one or when their siblings lacked insight into their mental illness [1]. With each hospitalisation, some siblings state experiencing a sense of helplessness as again the illness betrays both their sibling and the stability of the family unit [2, 20, 21]. Emotional exhaustion can also contribute to the sibling's depressed state.

Riebschleger [10] also identified an additional stage of Respite where the sibling experiences temporary relief of the effects of the mental illness as their sibling's illness becomes stabilised. However during this stage, the sibling may also constantly fear reoccurrence of illness. Acceptance and understanding of the illness provides siblings with a sense of stability and calm [10]. Being able to identify the individual from the illness and its behaviour also contributes to this stability.

Siblings hold serious concerns and fears for their loved one [2, 4, 24]. Some fear they too will become unwell due to the stress they feel and knowing that there is a potential hereditary risk of developing mental illness. Others are fearful of their sibling suiciding or becoming very unwell.

Having mental illness in the family affects the sibling's relationship with their unwell sibling, other siblings and their parents. Some siblings feel the need to compensate for their sibling with mental illness (also known as replacement child syndrome) and feel the pressure and need for perfectionism in school and work pursuits [3, 20]. Some siblings articulate their need to be involved within the mental health field to compensate for their sense of powerlessness and ineffectiveness with their own sibling [21]. Siblings may

also experience the 'silent child' phenomenon whereby they deny their own feelings in order not to add to the already present family burden [6].

Siblings speak of their own health problems and the effect of having a sibling with mental illness on their own well-being. Studies identify that illness-related stress is evident for siblings resulting in increased bouts of colds, and difficulties with sleeping, eating and concentration [9]. Their own mental health problems can be exacerbated as a result of caring for their sibling [17, 19]. The impact on physical health is also present with poor health habits such as lack of exercise and overeating identified by some siblings [1].

Having a sibling with mental illness can impact upon an individual's decision-making regarding family planning. Often, siblings hold concerns regarding beginning a family due to the genetic risk of having a child with mental health problems and hence may actively decide not to have children [17, 20]. Many siblings are fearful of their children having a mental illness and again, the impact of the illness on the individual and their family [1].

Daily challenges of having a sibling with mental illness

Having a sibling with mental illness can affect all aspects of daily living for siblings. Siblings can experience a two-fold impact of having a sibling with mental illness. Firstly, siblings may be affected by the challenges that their sibling faces regarding having a mental illness as often they provide support with their daily living struggles. But secondly, they may experience challenges in their relationships and interactions with their sibling, other family members and friends relating to their sibling, and are required to deal with the disruption that caregiving can cause on performance in the areas of work, study, leisure and self-care. These challenges can include the change and addition of roles for the sibling, coping with the illness, communicating and solving daily problems with the sibling living with mental illness, life planning, relationship disruptions, responsibility of care, communicating with family, navigating and working collaboratively with the mental health system, financial stress, household disruption and support, educational and career disruption and lacking time for leisure pursuits.

Often siblings find themselves taking on additional roles in relation to their sibling with mental illness, their parents and other family members. This leads to a duality in roles for the sibling in trying to meet the needs and expectations of siblings as well as parents [6, 21]. As a result, siblings often experience a conflict in supporting their sibling through mental illness whilst also supporting the needs of their parents. Some siblings find themselves as the confidant for their sibling but also the information gatherer for their parents [20, 21]. Siblings may feel powerless and helpless with their sibling's situation however they are often the one to take charge when their sibling becomes unwell.

Coping with changes in the individual's personality and behaviours is one of the greatest daily challenges voiced by siblings [3-6]. Some siblings speak of outbursts, and unexplainable and erratic behaviour causing a multitude of emotions including frustration, confusion, anger, embarrassment and sorrow. These behaviours interfere with the normal functioning of daily life as siblings are left to console their sibling or to remedy difficulties caused by such actions [2, 4]. The effort needed to respond and react to situations in daily life can be taxing on the emotional well-being of the sibling as well as disturbing their performance in life areas such as relationships, working, studying and self-care. This situation is further exacerbated by the illusive nature of mental illness inferring that siblings often have no prior warning as to when situations will arise and therefore it is difficult to predict and plan for these situations [4]. Some siblings identify that being separated from their sibling for a period of time would provide relief and time to re-energise.

Having a sibling with mental illness can potentially impact upon all relationships encompassing siblings, parents, spouses, children and friends. Many siblings speak of the strained relationship they have had with their brothers or sisters as a result of dealing with challenging behaviours and differences in opinion [1, 2, 21]. Discussion around mental illness and what helps or hinders is a topic that is sometimes difficult to broach with the sibling living with mental illness. This topic can also cause conflict within the family unit as some family members may be supportive of sharing information with the sibling with mental illness whereas others may not be as forthcoming or be conditional as to what information is shared [9]. Some siblings struggle to identify a window of opportunity as to when to discuss the possibility of treatment with their loved one as each sibling has different perceptions as to when treatment needed to be sought and the type of treatment that would be appropriate [4].

Some siblings identify that their brother or sister experiences difficulties with communication and problem-solving daily situations. Subsequently, difficulties with communication between the siblings can result in anger and frustration on both sides [7]. Communicating with a sibling who is experiencing disordered thoughts or delusional thinking is an area in which these siblings identify not having the skills to negotiate [1]. Communication difficulties can also make assisting with problem-solving challenging [7].

Strain on the family unit is evident in many sibling responses. Siblings speak of holding concerns for the well-being of all loved ones including their parents, other siblings and their own children [9, 17, 24]. Siblings often worry about the strain and stress that other family members, particularly parent primary caregivers, are placed under when a sibling is unwell [9]. Siblings experience a sense of guilt regarding witnessing parents under strain and feeling impotent to help.

Communication between family members and differing opinions regarding the well-being of the sibling with mental illness often causes friction within families. Contradictory opinions regarding setting limits and creating expectations for one's loved one, as well as how to best support the sibling, cause division within families [4, 24]. This often results in family members avoiding certain discussion topics and allying or distancing themselves with family members depending on their agreement on the topic. This process can foster alienation within families and a lack of normalcy in familial relationships [20].

Having a brother or sister with mental illness may affect the intimate relationships of their sibling and their spouse. Many siblings speak of the strain placed on their spousal relationship due to a lack of understanding, which can result in unmet needs and both parties feeling isolated [1, 2]. Negative experiences for siblings with previous spouses who did not understand the unique needs and situation of having a sibling with mental illness leads many siblings to lack trust and be ambivalent towards having any future partners [17, 20]. This further reinforces a sense of isolation experienced by individuals.

Siblings identify that the responsibility for caring for one's sibling exceeds beyond supporting their mental well-being. Caregiving also requires looking after physical problems of their sibling which result from having a mental illness or side effects of medication [4]. Some siblings express the emotional and physical toll of taking on the responsibility to care for their sibling, regardless of whether this care was requested by their sibling or not [5, 20]. With each relapse, some siblings blame themselves for not being able to stop the decline in health that their sibling is experiencing.

Siblings identify experiencing difficulty with their own life planning and decision-making. Decisions regarding where to live and short term and long terms plans for the future often take into consideration

the situation of their siblings, their health and care needs [17]. Furthermore, the experience of having a sibling with mental illness alters siblings' religious beliefs, political views and feelings about people with mental illness and other disabilities as they develop their understanding of living with mental illness and experience greater involvement in state and national healthcare, and support services [17].

One of the greatest challenges siblings face are their own and their sibling's involvement with the mental health system. Unsatisfactory and ineffective health services and treatments that are under-resourced, inappropriate and slow-to-respond, place greater pressure on siblings to look after sibling's well-being in areas which they have little knowledge [7]. This also means siblings' loved ones have not received timely and appropriate care and siblings have been left to witness the deterioration and suffering of their loved ones. Compounding this situation, difficulties in navigating the mental health system, communicating with health professionals and accessing information are common. Many siblings feel their concerns are often not validated nor listened to by health professionals, often resulting in responses that are insensitive and informed regarding their needs [4, 10]. Not having the knowledge of the roles of all members of the mental health system who are working with their sibling, as well as not knowing which pathways to use to seek assistance and clarification hinders and frustrates siblings attempting to obtain answers within a hierarchical and multifaceted system [4]. Consequently, siblings identify becoming disillusioned with a system that is meant to assist, and which instead further complicating their situation.

Parents and spouses are predominantly recognised as playing a caregiver role in the recovery of people with mental illness. Siblings appear to lack this recognition and as a result, experience difficulties with accessing sibling medical information due to confidentiality issues and lack of involvement in care planning regarding their sibling [4]. Subsequently, this sends conflicting messages to siblings as they are often called on during crisis situations however are not given the recognition as primary caregiver or support person in the treatment and wellness planning for their sibling [4, 10].

Many siblings provide assistance to their siblings with daily tasks in the form of instrumental support and emotional support. Siblings assist their brothers and sisters with various instrumental or household tasks such as shopping, cleaning, transportation, finances including lending money, and leisure activities which often come about when siblings are experiencing increased difficulty with disordered thinking and daily stress [3, 18, 26]. Siblings often provide support with emotional matters including coping with daily struggles, relationship difficulties and negative regard for oneself [24].

Landeen et al. [7] explored the present day concerns of siblings regarding their sibling with mental illness. The concerns included the degree of satisfaction and fulfilment that siblings with mental illness were perceived as experiencing, lifestyles issues such as housing and living independently, obtaining work, developing relationships as well as being able to effectively communicate and maintaining well-being through stabilising symptoms and medication management. In addition to present day concerns identified by Landeen et al. [7], Smith, Greenberg and Seltzer [8] identified future concerns that siblings held for their loved ones. These included having adequate financial and transportation support, engagement in leisure and social activities, concerns regarding the progression of the illness and meeting medical needs, and the availability of future resources and emotional support.

Siblings typically experience disruption to their life roles in areas of work, study, leisure, household management and caring for themselves. Caring for a sibling with mental illness can place financial stress on a sibling as they are required to use their own funds to care for and support their sibling [3]. Further adding to financial worries, caregiving can impact upon siblings' work and study performance. Siblings are

sometimes required to take time off work and study in order to support their sibling with medical appointments or to care for their sibling [1]. Whilst engaging in work and study, siblings state being preoccupied with concerns regarding their sibling and as a result, experience difficulty with concentrating on tasks. The overall impact can result in altered career and study plans for the sibling [6, 21]. Lively, Friedrich and Buckwalter [1] found that siblings identified that leisure activities were the activities greatest impacted upon as this life area was seen as less important to maintaining and often was viewed as less significant to other areas of living such as work and household maintenance.

Benefits of having a sibling with mental illness

Siblings identify a range of benefits to having a sibling with mental illness. Interesting to note, some of these are in conflict with the emotional and psychological impact and daily challenges that siblings have identified reflecting the unique and individualised experience of having a sibling with a mental illness. Literature revealed that not only does the process of living with a sibling who has mental illness contribute to one's personal development and growth but this also has positive ramifications and consequences on the nature and strength of all other life relationships. A very small but significant body of literature explores the benefits that come from having a sibling with mental illness as a result of the reciprocity of care and support that the sibling with mental illness equally provides to their own sibling.

Personal development and growth

- Greater understanding and tolerance [15, 16, 21, 24, 28]
- Increased patience [20]
- Greater empathy and compassion [15, 16, 19, 24, 27, 28]
- Deepened faith [20]
- More philosophical outlook [2]
- Greater sensitivity and consideration [2, 9]
- Stronger sense of self and identity [20]
- Personal maturation [5, 21]
- Personal stability [21]
- Increased resilience [16, 17, 21, 24]
- Enhanced coping skills [21]
- Greater resourcefulness [24]
- Development/Reinforcement of one's strengths/skills [2-4]
- Development of life reflection and appreciation to find meaning [2, 20, 21, 24]
- Increased knowledge about mental illness [24]
- Increased compassion and this was also seen with sibling's children
- Greater appreciation and value of self and contributions [2, 21]
- Healthier perspective and priorities [21]
- Development of advocacy skills [21]
- Need for perfectionism – motivation and achievement in work and study pursuits [1]

Relationship growth

- Stronger family unit and cohesion [1, 2, 6, 9, 20, 21, 24]
- Family members valued and appreciated the family unit and members [1]
- Greater support from spouse [1]
- Stronger sibling bond [5, 20, 21, 24]
- Valued the sibling bond and therefore being conscious of being supportive [9]
- Develop/broaden social support network [24]

Care and support

Sibling with mental illness provided care and support to their sibling and conveyed reciprocity in the sibling relationship.

- Supportive to family both emotionally and physically [9, 21]
- Sibling with mental illness would assist with finances (economic support) [18]
- Reciprocity of care and support [18, 26]
- Assistance with chores [18]
- Companionship [18]
- Give gifts [18]
- Provide affection [18]

Supports to living well with a sibling with mental illness

The following areas have been identified as being beneficial in one's efforts to live well and manage the stressors of having a sibling with mental illness. These aspects provide the basis for quality support in service provision for siblings of people with mental illness.

- Information - Regarding:
 - Knowing about mental illness, prognosis, treatment in order to aid in building understanding and empathy [1, 3, 4, 6, 7, 9, 27]
 - Personal testimonies in order to provide shared experience and sense of not being alone [24]
 - Age appropriate [6]
 - Phase specific in accessible formats (workshops, websites, information pack, psychoeducation family sessions) [3, 7]
 - Navigating the mental health system [2, 9]
 - Legal concerns [7]
 - Mental health legislation and right to obtain information [7]
 - Family planning [7]
 - Community resources [10, 21]
- Advocacy for people with mental illness and becoming more politically aware [1, 21]

- Acceptance of illness [20]
- Informal support network including:
 - Partners [15, 17, 28]
 - Family [2, 20, 21]
 - Close friends [2, 5, 20]
 - Special time with parents [2, 21]
 - Clergy [2, 21]
 - Advocacy organisations [2]
- Coping with illness/coping strategies including:
 - Identifying person from illness/externalising the illness in order to reduce feelings of anger and shame [4, 24]
 - Being able to relate to one's sibling [24]
 - Dealing with feelings of being overwhelmed and looking after own well-being through creating distance [5, 21]
 - Learning how to protect self through creating boundaries [24]
 - Dealing with behaviours [9, 21]
 - Responding to questions from peers [3]
 - Managing one's own anxiety and stress [2]
 - Creative activity [21]
 - Regular exercise [21]
 - Volunteer work [21]
 - Developing communication skills [2, 24]
 - How to be helpful in interactions/care planning [7, 9]
 - Resisting arguments regarding delusions [10]
 - Within family [21]
- Developing problem-solving skills [9]
- Provision of practical supports for sibling including: [10]
 - Food assistance
 - Housing assistance
 - Financial assistance
 - Medical care
 - Transportation support
- Peer support networks in order to share one's experiences that are: [2, 24]
 - Exclusively for siblings [9]
 - Outside of business hours e.g. hotline [9]

- Counselling or psychotherapy to address own psychological needs and to achieve balance in one's life [2, 3, 5]
- Satisfactory service provision and inclusive collaboration with mental health professionals and teams through:
 - Consistent, reliable and accessible contact/communication [4, 24]
 - Satisfactory, adequate services for ill sibling [21]
 - Accessible medical information regarding sibling [4]
 - Recognition of sibling role in treatment and care planning [4, 10]
 - Express empathy and compassion [24]
 - Discuss roles and responsibilities [10, 24]
 - Remove blame for development of illness [24]
 - Specialised in family systems [5]
 - Provide education [2]
- Family-oriented psychoeducation or therapy [10]
 - Focus on family strengths [10]
- Respite [10]

Barriers to living well with a sibling with mental illness

The following factors act as barriers for siblings in order for them to live well as well as to support their sibling to live well:

- Social stigma [2-4]
- Medicalisation of interventions including focus on individual treatments [10]
- Perception of illness by health professionals as being the failure of the family due to heredity patterns or family pathology. This implies blames. [10]
- Inadequate services and resources to deal with own trauma and pain [10]
- Lack of community resources [10]
- Interactions with siblings being crisis-based rather than holistic care planning [10]
- Lack of information regarding mental illness [2]
- Lack of resources and direction as to how to cope with sibling [2]

Conclusion

A considerable amount of quantitative literature has attempted to identify and quantify predictive factors of sibling involvement in support and caring for their sibling with mental illness [1, 2, 6-8, 16, 18, 19, 21, 23, 25, 28]. Empirical data has also aimed to quantify the burden of care experienced by siblings including subjective and objective burden, using measures of willingness to help and quality of life [4, 18]. The primary sample populations of this research have been the siblings of people who have either schizophrenia or an eating disorder [5, 6, 8, 9, 24, 25, 28].

A small but notable group of qualitative studies have looked at the lived experience of siblings of people with mental illness and preliminarily at the support needs of siblings [5, 6, 10, 17, 24]. However, these studies come primarily from the United States. There is an overall paucity of quantitative and especially qualitative literature exploring the experiences of adult siblings of people with mental illness in Australia.

In Australia, there is a lack of support and service provision for the siblings of people with disability. Furthermore, the needs of adults within this population have been dramatically overlooked with the vast majority of resources being directed at child siblings. Those resources that have been directed towards adult siblings are generic in their approach, viewing the needs of all siblings as being uniform. Service structure and allocation have not considered the differences in duration, effect on daily living and life course on the individual with mental illness compared with individuals with other disabilities and hence, the effect of this on their siblings.

A study using qualitative and quantitative measures to gauge the experience of siblings of people with mental illness whilst also attempting to identify and examine the past, current and future support needs of siblings in order to directly inform service provision has yet to be undertaken within Australia and abroad.

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