

Siblings Delphi Study Summary

Summary

The Delphi Study investigating the needs of siblings included an initial group of 40 consented participants with an average age of 40 years. The process included three rounds of survey questions, completed online designed to refine knowledge about the needs of the siblings of people affected by mental illness, and also their perception of the needs of their sibling.

Siblings identified that they needed time and support for themselves to successfully manage an optimal relationship with their sibling. They identified that they needed help and support in both supporting their sibling, but also in supporting their parents and dealing with complex family dynamics. Siblings were clear that while they needed time for themselves and their leisure and physical needs, they also need support to manage the on-going family relationships with all members of the family where a person is affected by a mental illness.

Presently, the main sources of support to the sibling of a person affected by mental illness come from their family and friends, and somewhat from the professions such as GPs and counsellors. There was some evidence that education and support that addressed the needs of siblings had been sought or found in the community sector, however this was not a universal 'port of call'.

The siblings of people affected by mental illness were primarily concerned with their sibling having access to all the resources that any other person would desire. They wanted good mental health and physical health support as well as community integration and a safe and secure home.

Most interesting were findings that although many of the needs of the person affected by mental illness that were identified by the sibling were not medical in nature, they identified that the sources of support on those matters were primarily medical in nature – GPs and other health professionals.

One of the other interesting findings was that some of the siblings identified the disempowerment and power imbalance that occurred both for themselves and their sibling from being labelled as a 'carer'. This set up a power imbalance between the siblings making the sibling more responsible for the other sibling's well-being where this responsibility was neither necessarily reciprocated nor fostered. This highlights the fact that carer funding is insufficient for the whole of family approach.

MIFA would suggest that these preliminary findings identify the need for a broader study, beyond this small group to validate the findings. MIFA would also suggest that there is a misfit between the information required and the location where the information was sought.

Recommendations

The findings of the pilot group lead MIFA to review its current role in the support for siblings (refer to program review) and MIFA will make recommendations for member organisations to develop practice changes to improve the education and support opportunities for siblings through innovative and novel approaches including web based training and support.

The findings of this survey in conjunction with the MIFA review of literature inform a process leading to the development of resources as well as education and support aimed specifically at adult siblings.

Participants and Siblings Characteristics

The participants were mostly female, most lived in NSW or SA and their average age was 40 years.

The characteristics of their siblings were more diverse. The siblings were equally divided between male and female and their primary diagnosis as reported by their siblings included schizophrenia, bipolar disorder and chronic depression.

Most siblings were not the primary carer but had regular face to face contact with their sibling as frequently as more than once a week, most often more than fortnightly.

Most of the participants reported that they had sought help in the past for themselves such as counselling, but relied mainly on the support of family and friends. The most frequently cited reason for not seeking additional support was the financial burden of support or the help desired did not exist.

Survey 2

The responses from survey one were analysed and survey two aimed to identify further detail of support needs of both the person affected by mental illness and their sibling in greater detail.

Question 1 sought to identify from a list of 31 options, the needs most frequently desired by siblings of people affected by mental illness to maintain themselves in good health.

1. Having time for myself
2. Eating well
3. Engaging in physical exercise or leisure activities
4. Providing support to our parents
5. Managing family dynamics and relationships
6. Communicating with sibling with mental illness
7. Dealing with differences in opinions with parents, other siblings and/or sibling with mental illness
8. Maintaining my sibling role rather than carer role
9. Taking on of support responsibilities from parents
10. Understanding how to support my sibling in their recovery

Question 2 sought to identify from a list of 20 the most frequently desired supports for the sibling of a person affected by mental illness

1. Counsellor or therapist
2. GP
3. Family
4. Friends
5. Partner
6. Information on mental illness
7. Advocacy and support organisations with a mental illness focus such as Mental Illness Fellowship of Australia and ARAFMI
8. Advocacy and support organisations with a focus on carers
9. Respite options for siblings
10. 24 hour helplines
11. Understanding and supportive work places

Question 3 then looked at the siblings opinion about what the person affected by mental illness might need

1. Accommodation and housing
2. Looking after their home and domestic chores
3. Social support and community integration
4. Employment and study
5. Transportation
6. Permanent care options
7. Financial and budgeting
8. Community follow-up and continuity of care between all service providers
9. Suicide prevention
10. Attending medical and other appointments

Question 4 then asked the sibling to rate the supports for relevance to the person affected by mental illness

1. GP
2. Medication
3. Psychiatrist
4. Counsellor or therapist
5. Medical and mental health services
6. Wellness Recovery Action Plans or Relapse Prevention plans
7. Home care support
8. Mental health trained workers in government departments such as Centrelink and Department of Housing
9. Psychosocial rehabilitation day programs
10. Community transport

Survey 3

A further refinement of needs for both siblings and their brother or sister affected by mental illness was investigated in this final round of survey questions.

Question 1 asked siblings to prioritise their responses based on previous input.

1. Communicating with sibling with mental illness
2. Having time for myself
3. Providing support to our parents
4. Managing family dynamics and relationships
5. Developing coping strategies for emotional resilience
6. Eating well
7. Maintaining my sibling role rather than carer role
8. Engaging in physical exercise or leisure activities
9. Developing coping strategies for practical situations
10. Taking on of support responsibilities from parents

Question 2 asked siblings to prioritise their responses in those sources of support for themselves in assisting their sibling.

1. Family

2. Partner
3. Friends
4. GP
5. Counsellor or therapist
6. Understanding and supportive workplaces
7. Information on mental illness
8. Advocacy and support organisations with a mental illness focus such as the Mental Illness Fellowship of Australia and MHC- ARAFMI
9. 24 hour helplines
10. Advocacy and support organisations with a focus on carers

Question 3 asked siblings to further prioritise the specific current and potential needs of their sibling

1. Looking after their mental well-being
2. Looking after their physical health
3. Social support and community integration
4. Attending medical and other appointments
5. Looking after their self-care needs
6. Accommodation and housing
7. Looking after their home and domestic chores
8. Community follow-up and continuity of care between all service providers
9. Financial and budgeting
10. Monitoring and care of co-morbidities e.g. other existing health problems besides mental illness

Question 4 asked the sibling to identify the sources of support for their the person affected by mental illness

1. Medication
2. GP
3. Psychiatrist
4. Wellness Recovery Action Plans or Relapse Prevention plans
5. Medical and mental health services
6. Counsellor or therapist
7. Home care support
8. Mental health trained workers in government departments such as Centrelink and Department of Housing
9. Psychosocial rehabilitation day programs
10. Mental health trained police

MIFA Siblings Project: Stage 1

Summary of Study Process

Stage 1

Process
<ol style="list-style-type: none"> 1. Questionnaire 1 undertaken by participants covering: <ul style="list-style-type: none"> - Lived experience of siblings having a brother or sister with a mental illness - Needs of siblings in relation to having a sibling with mental illness - Supports that have facilitated and hindered siblings' well-being - Quantitative assessment of siblings' quality of life using the Who-QOL 2. Analysis of responses: Responses covering lived experience, concerns and support needs individually thematically coded for identification of needs of siblings and supports identified as helpful or not helpful.

Stage 2

Process
<ol style="list-style-type: none"> 1. Questionnaire 2 undertaken required: <ul style="list-style-type: none"> - Participants to rate the relevance and important of needs and supports identified in Stage 1 as being <i>very important/relevant, important/relevant, slightly important, not at all important</i> or <i>unsure</i>. 2. The needs and supports categories were divided as to whether they are pertaining to the health and well-being of the sibling participant or to the health and well-being of the sibling with mental illness. 3. Analysis of results: Consensus for each need or support determined when participant responses reach 75% or more for one scale rating group e.g. (<i>very important/relevant, important/relevant</i>), (<i>slightly important/relevant</i>), (<i>not at all important/relevant</i>) or (<i>unsure</i>). 4. Needs and supports items that received a rating of <i>very important/relevant</i> or <i>important/relevant</i> constituted the items of Questionnaire 3 for prioritising by participants in terms of most important to least important.

Stage 3

Process
<ol style="list-style-type: none"> 1. Questionnaire 3 undertaken required: <p>Participants to prioritise all needs and supports from 1 to the total number of items in order to indicate which supports are most important to them and to their sibling.</p> 2. Analysis of results: Scoring of all needs and supports items calculated to identify most consensual needs and supports in order of priority.