Minimising collateral damage: family peer support and other strategies

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ABSTRACT

- The impact on family members of mental illness in a young person is intensely distressing. Symptoms that they cannot understand, and the stigma surrounding mental illness may lead to families feeling isolated in their distress.
- Family carers are reassured by talking with other families who have experienced the same or similar situations. The "Families Helping Families" program at ORYGEN Youth Health trains family peer-support workers, who are employed to provide information and support to families new to the service.
- Medical practitioners need to appreciate the importance of ensuring that families receive information and emotional support to help them cope effectively.
- Difficulties in helping family carers, often around perceived confidentiality restraints, need to be overcome so that collateral damage — family breakdown, persistence of symptoms, and behavioural maladjustments — can be reduced.
- Families who are supported can become advocates for improvements to mental health services for young people.

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The impact on family members of a young person developing a mental illness, such as psychosis, or a mood, personality or eating disorder, is extremely distressing. This first exposure to symptoms of mental illness is difficult for families to grasp.[1,2] There is no obvious cause. Families often cope through denial ("It's just a stage he or she is going through."), or they experience grief and loss at the adverse changes in their son or daughter. Furthermore, mental illness in young people is often complicated by drug and alcohol misuse.[3] Families feel unprepared and inept. Research indicates that some strategies used by family members that may not have been effective in controlling the patient's symptoms lead to further distress. Self-sacrifice ("giving up my life to care for my child") is an example.[4] Intrafamilial conflicts develop as the family struggles to comprehend the strange behaviour in their offspring. Family members may give up social contacts and employment, resulting in isolation and financial strain.

Most young people with mental illness live with family members, who become the primary carers — an unremitting task if the illness results in disability and social dislocation. Interviews with family carers soon after admission of their child to an early-intervention service found that over two-thirds (77.7%) suffered psychiatric levels of anxiety and depression.[5]

Yet, in spite of these research findings, and the experience of many mental health workers, not to mention the expressions of distress from families themselves, the needs of family members are still largely ignored.

Families and young people are often reluctant to seek out or accept "psychiatric" help. They do not know what to expect. Access to services sensitive to young people and their families can be a complicated, lengthy and frustrating process.[6] Doctors have difficulty accommodating the needs of family carers for a variety of reasons. These include issues of patient confidentiality, and the time restraints that prevent the longer consultations needed for giving family carers information and training in how to manage the complexities of mental illness behaviour.

Family carers who remain uninvolved in the treatment and care of their son or daughter, and who are emotionally unsupported during these initial phases, can develop poor coping techniques, making optimal management of complex situations difficult to achieve.

What do family carers say they need?

ORYGEN Youth Health, a clinical mental health service for young people aged 15–24 and their families, services a catchment area of about one million people in the north-west regions of Melbourne. ORYGEN clinical services comprise: the Early Psychosis Prevention and Intervention Centre (EPPIC), which provides treatment for young people experiencing a first episode of psychosis, and Youthscope, which provides treatment for a range of non-psychotic mental health disorders.

In May 2001, parents, grandparents and siblings of clients at ORYGEN Youth Health attended a focus group to explore the needs of family carers. The main issues for families, regardless of the psychiatric diagnosis, were:

- ***The need for information:*** Families need information about the illness and how to manage the behaviours arising from the symptoms of the illness. While families understand the need for a young person to develop a trusting relationship with his or her case manager, this should not rule out also helping the family, and patient confidentiality should not be used as a reason for excluding the family (except in certain circumstances). Often a young person is not even asked if he or she wants to have family members included.
- ***Emotional support:*** Family members need emotional support from the time of their initial contact with the service and for some time afterwards.

The recommendation from the focus group that families should be supported and can learn coping strategies from each other, became the basis for the "Families Helping Families" project at ORYGEN.

Families Helping Families

Contact with families is often minimal after the initial clinical assessment. This may relate to the perceived need to preserve patient confidentiality. Moreover, heavy caseloads make it difficult to find the time to help families, and there may be a lack of confidence in knowing just how to help families. Family peer-support "workers" employed in a clinical service would be able to overcome some of these problems.

1 Confidentiality and the involvement of family carers

- If a young person vetoes family contact, it is important for the doctor to determine why. Is the veto based on symptoms of mental illness (paranoia, depression) or are there genuine reasons (eg, abuse, a family in denial, a history of extreme family conflicts)?
- Doctors can explain to young people the benefits of having their family involved; for example, family members who don't understand the illness or the treatment can be unhelpful, and this can hinder recovery. When families are helped, they can be very supportive. Information and support given relates to a family's needs as carers.
- Clinicians can tell patients that information of a private nature will remain confidential between the patient and the treating clinician. (However, the law recognises a number of important exceptions to confidentiality, including circumstances in which the law, the public interest, or the patient's best interests authorise the disclosure of patient information. Doctors may, as part of their duty of care, have an obligation to disclose information, particularly if the patient's or anyone else's life is in danger.[8])

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2 Engaging with family members

When a young person is reluctant to seek help for mental illness

- Doctors can suggest that family members calmly encourage a young person to see his or her general practitioner. This is a normal thing to do for check-ups. It is best to focus on problems which the young person will see as "normal" — trouble with sleeping, concentrating, or eating; or feeling sad or anxious.
- In some cases, it may be appropriate for the doctor to assess a young person at home.
- If resistance continues, and the doctor and family agree that help is required — the young person is getting nowhere or is deteriorating — the doctor should contact the local mental health service. If there is concern that the person may be a danger to himself or herself or others, police intervention may be required. The family will need support to do this, as it is a very difficult decision.

Helping family members describe behavioural change

- Doctors can suggest that family members write down, in point form, all the behaviours that indicate to the family that "something is not quite right". What behavioural changes have made them concerned? What behaviours seem to be more than "just problems in growing-up"?
    - Ask families to give examples of specific instances of abnormal behaviour, not generalisations. What has he or she been doing and saying? For example, instead of: "Joe is very shy these days", say "For the past week, Joe has only come out of his room to get food". Instead of "Mary avoids us, doesn't want to have anything to do with us", say: "Last night Mary would not talk or eat with us. She says we are plotting against her".
    - If there is concern about suicidal thoughts, establish whether these are vague notions like: "There's no point to life. I might as well be dead" or the young person describes actual plans. Specific instances will help families to pinpoint clearly what they see as abnormal and/or urgent. It will help the doctor to assess whether there is cause for concern and the need for help.
    - Having specific examples of behaviour that is "out-of character" for the young person helps family carers overcome the confusion and embarrassment they can experience in front of a clinician. When family members talk about these problems, they start to wonder whether they are "making it up" or exaggerating the issues. They become concerned about what the doctor will think of them, and may withhold information that could be helpful.
- A useful brochure called "Something is not quite right — getting help early for mental illness" can be obtained from SANE Australia (email: admin@sane.org). This brochure is helpful for both doctors and families. It has a checklist of behaviours that are considered "normal but difficult", and behaviours that are considered "abnormal for that person".

Psychiatric disorders and drugs and alcohol

- Young people developing psychiatric disorders may use drugs and alcohol to make them feel better, but this behaviour signals their need for help. GPs can make a medical assessment to determine if there is an underlying psychiatric problem requiring further attention (and referral to a psychiatrist or mental health service) or if referral to an alcohol and drug agency for treatment is appropriate.

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A program for training peer-support workers was developed at ORYGEN Youth Health. The training consists of seven 90-minute sessions:

1. Learning ways to use their "lived experiences" to help other families.
2. Telephone or face-to-face support, using interpreters to facilitate communication for families with cultural differences.
3. Guidelines for the management of emotional distress.
4. Guidelines for the management of illness behaviour.
5. Informing families about mental health services.
6. Understanding "boundary issues" — how to work with clinical staff.
7. Running a family support group.

The Families Helping Families project has three components:

- ***A monthly support group*** where families share experiences. They become aware that mental illness in adolescents and young adults is common, that they have not caused these conditions, and that there are many families facing similar problems.
- ***A family resource room*** where families have access to information about mental illnesses. They can talk with the family peer-support workers.
- ***Telephone information and support*** — the family peer-support worker phones the new family. They introduce themselves as family carers who have been through the ORYGEN program, and explain that they are phoning to see if they can be of assistance. These calls overcome the reluctance of many families to reach out for help. The phone calls:
    - Provide family members with emotional support and information at a time when they often do not know which way to turn. When support is given by family "role models" (families who have been through the same or similar experiences), it serves to reassure, allay fears, and show that there is every reason to be hopeful that situations can improve.
    - Explain the "psychiatric system". Families reflect the stigma associated with mental illness and are concerned about psychiatric care. Emphasis is placed on reassuring them that prescribed medications are important components of mental health care.
    - Direct family carers to information sessions given by clinicians, to the family resource room, and to the support group.
    - Document difficulties with which the family is coping.
    - Encourage family carers to take their concerns to the doctors and case managers.

Our service believes in including family carers as part of the treatment and care team. Many families are diffident and difficult to engage.[7] Family peer-support workers play an important role in helping families engage with the service.

These phone calls are made without having to ask the patient's consent. Family carers need support in their own right and are entitled to receive all the help they need.

There are exceptions; the family may be unaware that their son or daughter has been admitted. If there are valid reasons for not wanting the family to be involved, or the family has a history of extreme difficulties (eg, intrafamilial sexual abuse), case managers will request that the family not be contacted until further notice.

Young people need to be reassured that family peer-support workers receive no information about them, and therefore cannot breach confidentiality.

Discussion

Through the Families Helping Families program, families gain useful information and support from other families experiencing similar situations. If it becomes apparent that the problems of mental illness are ongoing, doctors can refer families to support organisations. The SANE Australia Helpline (1800 688 382) and the SANE website (http://www.sane.org) provide information about family support groups and organisations. SANE also has a wide range of publications on many topics which family members find useful.

Difficulties for doctors arise if young people are adamant that family members are not to be contacted, but most young people if asked, particularly when acute symptoms of mental illness have subsided, are willing to have their family involved (Box 1).

Doctors may be approached by anxious family members when their son or daughter refuses their request to seek medical assistance. It is not helpful to the family to be just told to "bring him or her in". If they could, they would. And it is impossible for doctors to give treatment without actually seeing the young person. Box 2 gives suggestions for dealing with this problem, as well as the best ways for parents to describe the behavioural changes of incipient mental illness.

Collaboration with clinicians in treatment and care in the early stages of mental illness, supported by the experiential sharing and emotional support gained from family peer-support workers, develops the personal and social resources that families need to enhance their caring role.

In turn, many families who feel valued and empowered by professional services have the incentive to improve mental health care by raising community awareness — through speaking in schools, churches, clubs, other organisations, and through targeted political advocacy.

Families need to be heard and supported at an early stage, so that much of the unnecessary trauma experienced by young people with mental illnesses and their families can be alleviated.

Competing interests

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