Who’s caring for whom? Living with parents with mental health problems

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Increased Risk for Young People Living with Parents with a Mental Health Problem

A number of studies have observed high rates of emotional and behavioural disturbance in children of parents with mental disorders (Beardslee et al., 1986; Kulyer et al., 1980; Pellegrini et al., 1986; Welner et. al., 1977). Such children are at an increased risk of developing mental health problems themselves (Devlin, 1996). Genetic factors are responsible for a proportion of this risk, but environmental factors also exacerbate the risk for children living in families affected by parental mental illness. Mental disorders affecting thought, behaviour and mood in parents can impact negatively on the interaction of parents with their children. High levels of conflict and discord have also been observed in such families (Noh & Avison, 1988; Rutter & Quinton, 1994) and in families where external social supports are often lacking (Hill & Balk, 1987; Noh & Avison, 1988). Many such families are also affected by economic hardship.

The Human Rights and Equal Opportunity Commission (HREOC, 1993) inquiry into mental illness, also known as the Burdekin Report, noted that in addition to serious family disruption, children of parents with mental illness are highly likely to have stressful school and social experiences. The report also noted that such children ‘can develop emotional, behavioural, social and psychiatric problems because their needs are overlooked by existing services where the needs of parents with mental illness are seen to be of paramount importance’ (HREOC, 1993, p. 498). The Melbourne-based Coalition of Child and Adolescent Mental Health Professionals told the inquiry: ‘The rights and needs of children whose parents suffer from a major mental illness are not the direct responsibility of any service’ (HREOC, 1993,
p. 498). The Report found that Australia has failed to provide adequate services for young people whose parent (or parents) are affected by mental illness.

It is, therefore, imperative that interventions aimed at both preventing the onset, and reducing the burden, of various mental health problems in young people are developed. The development of interventions which promote the quality of life of young people living in such families is also essential (Pope, 1997).

A number of programs have been developed to address the needs of young people living with parents with mental health problems, both overseas (Beardslee et al., 1992; Beardslee et al., 1996; Hill & Balk, 1987) and in Australia (see Devlin, 1996, for a review of selected programs). Although several of the existing programs have been evaluated, there is little information available about the ways in which these programs are appropriate for young people from culturally and linguistically diverse backgrounds.

Impact upon Young People from Culturally and Linguistically Diverse Backgrounds Living with Parents with Mental Health Problems

There are a number of social, cultural and political circumstances that are unique to the experience of young people of non-English speaking backgrounds (NESB). Sensitivity is required in addressing these matters. Studies indicate that people from NESB underutilise mental health services (McDonald, 1991; McDonald & Steel, 1997; Ridoutt & Filis, 1992; Trauer, 1995). However, there is no evidence that psychiatric morbidity is lower among people of NESB. Service underutilisation is likely to be due to various barriers to service access and culturally determined attitudes to seeking help. Thus, parents of NESB with a mental disorder may have low levels of access to appropriate treatment, information, rehabilitation and support services compared to majority populations. These barriers to service for parents of NESB are also likely to act as barriers for programs targeting young people and families affected by parental mental disorder and may substantially increase the burden of care experienced by family members, including the children. This burden may fall increasingly on the children, especially if the partner of the affected person also lacks high-level English language skills and knowledge of the health system and available services.

Research into the mental health of young people of NESB immigrant and refugee families has found intergenerational conflict to be an important issue (Klimidis & Minas, 1995). Young people from NESB may be exposed to conflict between the individualistic values of Australian society and the traditional values of their parents. Culturally determined values concerning the roles and responsibilities of parents and children, in addition to parental fears about the influence of mainstream Australian customs, may also affect NESB parents’ willingness to allow their children to participate in programs targeting young people.
Young people from refugee families may face additional problems. Refugees, particularly those who have experienced torture and trauma in their country of origin, are at extremely high risk of experiencing mental health problems. Community-based studies conducted in the USA and Australia have found the prevalence of post-traumatic stress disorder and depression to be fifty per cent or higher in a number of traumatised South-East Asian populations (Carlson & Ross-er-Hogan, 1991; Silove, 1994). Rates of mental health problems have generally been found to be positively correlated with levels of exposure to traumatic events. While the prevalence of these disorders and levels of symptomatology have generally been found to decline over time with settlement, high levels of depressive symptoms may persist (Beiser, 1988; Hinton et al., 1997).

Difficulties experienced during settlement can exacerbate stress and increase the risk of mental health problems among refugees (Arocé & Coello, 1994). Prolonged separation of families during flight can lead, on reunion, to increased levels of family conflict and family breakdown. Loss of multiple members of family and friends before, and as a result of, migration means that many refugees are exposed to prolonged bereavement and lack of support networks. Such networks are widely recognised as providing support and reducing the impact of various mental health problems. For many refugees the experience of loss of family and friends is complicated by a sense of guilt at having survived and reached safety, as well as uncertainty about the fate of missing loved ones (Hodgkinson & Stewart, 1991). The gradual resolution of grief that usually occurs in the bereavement process following a loss through confirmed death is often impossible for many refugees who have lost loved ones to an unknown fate. In addition, levels of unemployment are very high among some refugee communities. Furthermore, hostile reception in the host society has also been associated with poorer mental health outcomes for refugees and other migrants.

The National Health and Medical Research Council (NHMRC) report on depression among young people (1997) indicates that young people growing up in such families have increased exposure to risk factors for mental health problems, particularly depression, whether or not they are directly exposed to traumatic events. Depression in parents is a risk factor for depression in young people (NHMRC, 1997). Thus, the high prevalence of depression in adult refugees is an indication that their children are at increased risk. Children from refugee families may experience emotional problems, including social withdrawal, chronic fears, depression, overly dependent behaviour, sleep disturbance, problems at school and difficulties relating to peers (Canadian Task Force, 1988; Jayasuriya et al., 1992). A study of adolescent and young adult Afghan refugees has found a high correlation between rates of mental disorder in young people and levels of maternal distress (Mghir et al., 1995). For families affected by torture and trauma, the children’s experience and risk of developing mental health problems may be complicated and increased through their
own exposure to pre-migration trauma or through vicarious exposure by means of their parents’ experiences.

The high levels of distress experienced by many refugee parents may lead to under-recognition of the problems that their children may be experiencing. Combined with fears and concerns about the intentions of government services, this may create considerable barriers in reaching members of this specific group.

Research into the area of young people living with a parent with a mental health problem has effectively ignored the diversity of the Australian population and the impact of language, culture and resettlement. Similarly, programs targeting young people living with a parent with a mental health problem have been developed, trialled and evaluated with majority populations, without adequately considering how minority communities could be engaged, and programs tailored to meet their needs. Hence, the needs and concerns of young people from NESB who have a parent with a mental health problem need to be investigated and addressed. The effectiveness of culturally appropriate programs targeting such young people need to be evaluated in a way that addresses the diversity of the population targeted. This requires extensive consultation with young people of NESB, as well as their parents. Their ongoing involvement with regard to program development, delivery and evaluation will facilitate the effectiveness of any interventions (Sozomenou et al., 2000). The study reported below addresses these factors.

**Aim of the Present Study**

The aim of the research project was to promote the mental health of young people from NESBs living with a parent with a mental health problem.

This report focuses on the first stage of the project and the interviews conducted with workers in the fields of mental health, health and youth. The paper provides an analysis of the workers’ comments relating to:

i. key issues facing young people living with a parent with a mental health problem; and

ii. key issues facing parents with a mental health problem.

**Methodology**

*Collaborative framework*

This collaborative research project is being conducted within the South Western Sydney Area Health Service and is being coordinated by the Transcultural Mental Health Centre. An Advisory Committee was established, made up of the: Transcultural Mental Health Centre; South Western Sydney Area Health Service (SWSAHS) Health Promotion Unit; Gaining Ground Project based at the SWSAHS
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Paediatric Mental Health Service; Service for the Treatment and Rehabilitation of Torture and Trauma Survivors (STARTTS); and Fairfield/Liverpool Cross-Cultural Mental Health Program. The Advisory Committee played a vital role in guiding the project.

Research design

The research project has three interdependent stages.

Stage One — to conduct a community needs assessment/consultation with the following:
- Young people between the ages of 12 and 24 years who are of Vietnamese, Cambodian, or Spanish-speaking background, who have a parent with a mental health problem. The project has focused on the largest language groups in the SWSAHS that also have a high proportion of refugees.
- Parents from Vietnamese, Cambodian or Spanish-speaking backgrounds who have, or are experiencing, mental health problems and who have a son/daughter between the ages of 12 and 24 years. ‘Mental health problems’ include a spectrum that spans from severe psychiatric illnesses to less severe psychological and emotional concerns.
- Mental health/general health workers, youth workers, bilingual counsellors and other stakeholders in the community.

Stage Two — utilisation of the results of the consultations to develop appropriate material to promote the mental health of young people of Cambodian, Vietnamese or Spanish-speaking backgrounds living with a parent with mental health problems.

Stage Three — involves the implementation and evaluation of the interventions.

Ethics Committee clearance

Approval to conduct the study was obtained from the SWSAHS Research Ethics Committee. Ethics Committee approval was required primarily for the purpose of collecting data from clients of mental health and youth health services. Consent forms were translated into the three community languages, for both parents and young people.

Questionnaire design

A structured questionnaire was used that incorporated both closed and open-ended questions. Overall, the questionnaire for service providers examined:
- the needs of young people living with a parent with mental health problems and of their parents;
- the services that have been developed for such young people and their parents;
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- the services that are needed to meet the needs of such young people and their parents;
- the efficacy of support and psycho-education programs targeting such young people and parents from NESBs; and
- the professional development needs of staff working with such young people or their parents.

**Interviews and focus groups**

As part of the needs assessment two main methods of data collection have been used: individual interviews and focus groups. The total number of individuals who participated in an interview or focus group were:

- 60 workers encompassing managers, mental health workers, bilingual workers/counsellors, health workers, youth health workers/counsellors, youth development workers, psychiatric-nurses, primary-nurses, community health-nurses, health promotions workers, school counsellors, community workers, welfare workers, community settlement workers, case managers and a solicitor in the SWSAHS;
- 22 young people from Spanish, Vietnamese or Cambodian backgrounds with a parent having a mental health problem; and
- 31 parents from Spanish, Vietnamese or Cambodian backgrounds with a mental health problem.

**Content analysis**

The data were content-analysed using the techniques outlined by Berg (1989) and Patton (1990). This entails an ‘open coding’ approach (Berg, 1989, pp. 117–18) which is conducive to the aim of ensuring that emergent themes are induced from or ‘grounded’ in the data (Glaser & Strauss, 1967) rather than being entirely deduced from, or shaped by, a set of predetermined concepts.

There were three main steps to the content analysis procedure:

**i. Collation of ‘meaningful clusters’ of data**

The collation procedure involved systematically reading through each interview transcript and:

- identifying ‘units’ of information;
- categorising each unit; and then
- ‘cutting and pasting’ each unit into a single document that was a collation or combination of all the interview data for the three groups of respondents.

**ii. Description of meaningful clusters**

Following collation of the raw data from individual interviews into meaningful clusters, these clusters were then systematically described. Consistent with Patton’s
(1990) advice to separate the process of data ‘description’ and ‘interpretation’ as much as possible, the focus was on simply describing the data using concepts and terms utilised by the respondents themselves, and in ‘such a way that others reading the results can understand and draw their own interpretations’ (Patton, 1990, p. 375). Every effort was made to ensure no respondents could be identified in this material.

The importance of themes was determined according to three main criteria:
• the numbers of respondents who provided information relevant to that theme;
• the total quantity of information relevant to that theme; and
• the quality of the information (e.g. how strongly respondents felt about the issue).

iii. Interpretive analysis
The third stage of data analysis involved identifying, describing and interpreting the most important themes emerging from a consideration of the data from the respondents.

Results: Staff Perspectives

Overall, it was found that the Cambodian, Vietnamese and Spanish-speaking communities shared common experiences and concerns. Therefore, the key issues that are presented below impact on all three language groups. The study identified factors that impact specifically on young people from the three language groups with parents who have a mental health problem, in addition to the factors that would normally be faced by young people.

Staff were asked to identify the key issues and concerns affecting both young people and their parents across the three language groups targeted. The issues and concerns raised by workers have been categorised into nine main themes. These were:
• effects of ineffectual parenting;
• ‘parentification’ of young people;
• ineffectual and inappropriate discipline;
• cross-cultural issues;
• impact of the resettlement process;
• impact of torture and trauma experiences on parenting;
• lack of knowledge about mental health;
• isolation and barriers to accessing services; and
• decline in academic achievement in young people.

Effects of ineffectual parenting

Inconsistent parenting was summarised by workers as unstable nurturance of the emotional, social and physiological development of young people and the absence of
appropriate constraints and boundaries. Staff felt that ineffectual and inconsistent parenting could result in young people being physically neglected and psychologically abandoned. It was noted that the effects of torture and trauma also may contribute to inconsistent parenting.

Staff reported that families need to provide a coherent family structure for young people. This structure, however, may be chaotic and inconsistent because of the mental health problems of parents. Young people may not have adequate role models and may experience difficulties with social constraints and boundaries. Without stability and adequate boundaries, it was found that young people were not able to adjust emotionally, psychologically, developmentally, academically and socially. If the young person has lived in a chaotic environment, then their perception of the world and their location within it will be affected. A young person learns to interact with the world through their parents. As a consequence, if the parent interacts in a maladaptive way, then the young person may learn to interact maladaptively.

Parents from refugee backgrounds may experience difficulties in being effective parents. Ineffectual parenting may be a direct result of traumatic events and circumstances that interrupted the learning of parenting skills. Staff identified examples from all three language groups demonstrating that parents who had lost their own parents during childhood or adolescence, had had limited opportunity to learn appropriate parenting skills.

Some parents with a mental health problem did not have the ability to take care of themselves, nor were they able to take care of their children. Examples such as the provision of basic needs, adequate food, clean clothes, and regular school attendance were noted. Some young people experienced health problems that were related to poor nutrition.

'Parentification' of young people

'Parentification' was described as the young person taking on the roles and responsibility of a parent. Staff noted that some parents with a mental health problem were dependent on their children, both emotionally and as a conduit to the outside world.

Some young people became carers for their parents and provided them with emotional, social and practical support, not only for the parent with a mental health problem, but also for younger siblings. This may have led to young people being forced to assume adult responsibilities before they were old enough, and consequently resenting their loss of childhood. Young people in such circumstances were not given the opportunity to learn from their mistakes in a supportive environment. School absenteeism was often raised by staff as being the direct result of a young person having to care for an unwell parent.

Parents' reliance on their children was further exacerbated when families from the three language groups resettled in Australia with no extended family support. In
such situations some parents depended on their children to act as interpreters, to pay bills and for the practicalities of daily life. As a consequence, some young people led their lives according to the needs of their parents and were unable to undertake normal developmental activities and enjoy their childhood.

Staff noted that young people with a parent with a mental health problem have experienced a range of emotions, including anger, fear, loss, grief and sympathy. Young people were perceived to internalise expectations about what parents should be like and often became disappointed, angry and resentful because their parent did not fit into their expectations of an ‘ideal parent’.

**Ineffectual and inappropriate discipline**

The issue of discipline was raised by the majority of staff interviewed. There was a general perception that parents from NESB used stricter, less flexible, more physical forms of punishment than did English-speaking parents. Staff reported that parents who have mental health problems had difficulty disciplining, were inconsistent in disciplining and misunderstood the way they could discipline their children in the Australian context. A problem area identified by staff was children who were out of control due to ineffectual disciplining. The issue was exacerbated when parenting techniques learnt in the country of origin were not congruous with those in the host environment.

It was perceived that parents from the targeted language groups conceptualised physical punishment as the only form of discipline they could competently administer to control their children. Staff noted that most parents were unaware of alternate strategies by which they could effectively discipline their children. Staff reported that parents were often not carrying out their traditional disciplining methods as they feared they would be reported to the Department of Community Services or the police. In addition, young people who had knowledge of these services could use this information to threaten their parents. Some staff mentioned cases in which young people had called or threatened to call the police because their parents had used physical punishment to discipline them. As a consequence, the majority of parents felt helpless and angry. They were unable to rely on their traditional disciplining methods, and they were unable to effectively put into practice disciplining techniques acceptable to mainstream Australia.

**Cross-cultural issues**

*Language* — Language was seen as an overriding theme, interacting with and exacerbating many of the issues affecting young people and their parents. Lack of English proficiency was seen to be a critical issue that affected both parents and young people from culturally and linguistically diverse backgrounds. Staff noted that young people were able to learn English at a more rapid rate than their parents. This was seen as contributing to a communication gap between NESB parents and
their children. The communication gap was further exacerbated due to parental mental health problems.

Cross-cultural and intergenerational conflict — Cross-cultural and intergenerational conflicts were identified by most staff as key issues affecting young people and their parents. Family conflict was reported as an issue across all three communities. It was exacerbated in families with parental mental illness and was a leading cause of family breakdown. Staff noted that parents usually live according to their culture of origin, but young people were more likely to adopt the Australian way of life. Staff observed that young people were living in two cultures. Consequently, they were experiencing internal conflict and were blamed by parents for adopting aspects of the Australian culture of which the parents did not approve. A variable that influenced intergenerational conflict in NESB families was how different the parents' culture was from the Australian culture.

Racism — Young people were noted to be victims of bullying, discrimination, and racism. The political climate exemplified by racism at the time that the interviews were conducted had created a sense of panic in some refugees. Staff reported that this had resulted in the re-traumatisation of some of their clients who were of refugee background.

Impact of the resettlement process

The difficulties families encounter in the resettlement process (such as establishing themselves in the country, finding appropriate housing, securing a job with a steady income, and learning a new language) were key issues that affected the Cambodian and Vietnamese communities and, to a lesser degree, the Spanish-speaking community. As a consequence, it was reported that all of the parents' energy was devoted to the resettlement process. In many cases this resulted in the masking of mental health problems, which often surfaced after the initial resettlement process. The immediate demands placed on parents to negotiate the ongoing needs of their families during resettlement also resulted in some children's emotional needs being neglected.

Impact of torture and trauma experiences on parenting

The torture and trauma that the Vietnamese, Cambodian and some Spanish-speaking communities have experienced, occurred largely during their escape from their country of origin or while living in a refugee camp. Staff reported that the refugee process had destroyed the concept of family for many of the refugees. Young people had often assumed the burden associated with living in a refugee camp since their parents were emotionally and physically exhausted.

Some staff reported that young people who did not go through a refugee camp or who were not directly traumatised may have been exposed to secondary
traumatisation as a consequence of their parents’ reflections on their horrific experiences. This may have an impact on the young person’s mental health immediately or in later life.

Staff also mentioned that parents who have experienced extreme difficulties and who have remained together for purposes of survival, may find that their marital relationship deteriorates or ends once settled in Australia when the stress that bound them together has abated.

**Lack of knowledge about mental health**

Across the three communities, parents and young people were noted by staff as lacking knowledge about Western concepts of mental health. Families were also unaware of the effect that a parent’s mental health problem has on a young person.

Staff reported that young people and their parents were not familiar with mental health services, counsellors and youth support services. Parents’ unfamiliarity with such services partly relates to the different welfare and health systems that exist in the parents’ country of origin. In addition, Western definitions and concepts of mental health, which may not be easily translated, further impact on parents’ and young people’s access to mental health services.

Parents from the three communities were likely to present with a range of somatic complaints (e.g. backache, headache) as symptoms of psychological distress. Staff reported that Vietnamese and Cambodian parents were more likely to be concurrently using two models of intervention, traditional models involving religion and physical therapy, as well as the Western psychiatric model. Even when the person of Vietnamese or Cambodian background was being treated by a psychiatrist, they might also be relying on traditional healing practices (e.g. heat therapy, massage, acupuncture, natural therapies). Hence, it was concluded that the provision of a wholistic approach to service delivery is necessary.

Staff found that young people who had a parent receiving a service were more easily targeted by their parent’s mental health worker. Staff reported that young people and parents were more likely to access a service that had a positive and culturally sensitive profile in the community.

Staff indicated that parents from the three language groups have a negative image of youth services. Staff reported that youth services were perceived by parents to break up families, persuade children to leave home and experiment with drugs. Also, the cross-cultural inappropriateness of material displayed in youth services acted as a barrier to parents permitting their children to attend.

Some staff highlighted the need to establish a trusting relationship with parents to enable staff to provide assistance and guidance to a son or daughter.
Isolation and barriers to accessing services

Isolation was a key factor affecting both young people and parents who had experienced a mental health problem. Staff reported that parents regularly commented that they felt alone because no one could understand their everyday reality. Many parents perceived their own experiences to be unique. Young people similarly felt isolated and unable to bring friends home due to the stigma associated with mental illness.

The isolation experienced by young people and their parents was exacerbated by poor public transport availability which hindered their access to services and community supports. The lack of information about mental health services, as well as their mental health problem compounded feelings of isolation.

The absence of extended family support within the Cambodian and Vietnamese communities also contributed to individuals feeling isolated and unsupported. Without the extended family networks, individuals often struggled to deal with their concerns until the situation reached a crisis point.

Decline in academic achievement in young people

Staff emphasised that most young people who had recently arrived in Australia were experiencing difficulties adapting to a new culture and language, new systems and services. These young people placed themselves under extreme pressure by trying to achieve the same goals at school that they had previously achieved. Staff reported that parents also placed high expectations on their children to succeed academically, and this created a stressful environment for young people. However, due to language difficulties their performance deteriorated. The need for support in such situations was seen to be extremely important, but such support was not always available if a parent had a mental health problem.

Staff identified that young people who have spent extended periods in a refugee camp are also likely to have had a limited education, or disrupted education. Therefore, placing them in the academic year that accords with their age is an arbitrary decision. This was found to compound feelings of powerlessness that refugee young people may experience.

An issue identified by some staff was the lack of school administrators’ ‘mental health literacy’. In addition to this, school administrators are often unaware of the refugee and migrant experience, and how such experiences can contribute to feelings of loss, alienation and isolation in the young person. It was difficult for other students, or even the teacher, to comprehend that young people had experienced trauma or lived in a refugee camp. The young refugee was now considered a member of the class without consideration of the impact that their previous experiences were having on their current functioning.
Future Directions and Recommendations

Information derived from interviewing staff, young people and parents will be utilised to develop service recommendations and a program tailored to meet the needs of young people from NESB living with a parent with a mental health problem. The third stage of the project will involve delivery and evaluation of the interventions.

The findings presented raise a number of considerations for the design and delivery of additional programs for young people from NESB living with a parent with a mental health problem. These include the need for:

- public awareness campaigns to enhance the community’s knowledge and identification of mental health problems, to increase community resilience and reduce stigma through the provision of translated material in a diverse range of mediums, such as ethnic radio programs and print campaigns;
- research to examine parenting across cultures and the impacts of such parenting on young people within the Australian context;
- a stocktake of evidence-based youth programs and parenting programs;
- staff training aimed at examining child and adolescent development and parenting across cultures, as well as increasing sensitivity and cultural awareness;
- staff training about the needs of young people of NESB living with a parent with mental health problems;
- the collaboration of relevant services;
- the development of good practice protocols for managing the care of young people whose parents have a mental health problem;
- the provision of support groups and psycho-education programs for young people and their parents; and
- extensive consultation with young people, as well as parents, of NESB on the development of future programs.

Based on the preliminary findings from the interviews conducted with staff, it is recommended that, for young NESB people who have a parent or parents with mental health problems, programs address:

- the impact of inconsistent parenting on young people;
- young people adopting the role and responsibilities of parents;
- young people’s experience of discipline;
- attitudes towards mental illness, knowledge of mental illness and symptomatology within linguistically and culturally diverse contexts;
- knowledge of support services;
- coping with stigma and discrimination;
- the effects of migration, resettlement, the refugee experience, as well as torture and trauma on parents and young people; and
the effects of secondary trauma on young people’s mental health; and cross-cultural and intergenerational conflict.

The research findings indicate a negative impact on the mental and physical wellbeing of some young people living with a parent with a mental health problem. The concerns faced by such young people and parents of Cambodian, Vietnamese or Spanish-speaking backgrounds are multiple, complex and synergistic. The challenges of understanding and addressing their needs are the responsibility of mental health and youth health services, but they also must be addressed and linked in with other relevant systems (education, child welfare, juvenile justice), as well as informal resources such as community groups, churches and community leaders. This challenge needs to be addressed in partnership with young people of NESBs living with a parent with a mental health problem, and with the parents of those young people.

References


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