Unless the adult is suitably affluent it is not economically worthwhile for solicitors to become involved and they decline to do so. The local authority may then find there is no one to 'hold' the guardianship, leaving the vulnerable adult at the mercy of their own incapacity.

Adherence to the principle of the 'least restrictive option' was also raised in relation to the definition of incapacity and the criterion to 'retain the memory of decisions'. It was argued that if a consistent decision, using sound reasoning and in keeping with an individual’s life preferences, is made, then the ability to retain the memory of it is less relevant than the preference itself.

In summary, the medical profession has embraced the legislative changes inherent in the AWIA. Dr Michael Wilks, chairman of the British Medical Association ethics committee, stated:

'These responses are good news for patients, carers and doctors . . . the intention of the legislation is to promote patient choice, and to enable health professionals to support independent decision making by vulnerable adults.' (Wilks, 2004)

Consultant psychiatrists in Scotland appear to endorse these sentiments and demonstrated good knowledge of the AWIA. Their familiarity with this legislation compares favourably with their knowledge of the Human Rights Act 1998 (Passmore & Leung, 2003) and mental health law (Humphreys, 1998).

Limitations of the study

Limitations of this study include a selection bias because of the postal distribution; the study took place some time after the induction programmes with likely reductions in retention and recall of information; for pragmatic reasons the study could not be extended to other disciplines in medicine or to primary care clinicians and it was not possible to arrange a comparison group. None the less, findings from this group are important irrespective of whether they differ from other doctors’ experience of the legislation.

Acknowledgements

Thanks to Dr Mark Taylor and Dr Alastair Hull for their help with an earlier draft of this article.

References


Adults with Incapacity Act (Scotland) Act (http://www.opsi.gov.uk/acts/acts2000/asp_20000004_en_1).


Justine McCulloch Consultant Psychiatrist, Kildean Hospital, Stirling FK8 1RW, email: justine.mcculloch@nhs.net

Prevalence of parental mental illness in Australian families

DARRYL JOHN MAYBERY, ANDREA E. REUPERT, KENT PATRICK, MELINDA GOODYEAR AND LIN CRAE

AIMS AND METHOD

To provide multiple estimates of the numbers of Australian and Victorian families and children living in families where a parent has had a mental illness. We used the Australian Bureau of Statistics Victorian Mental Health Branch service usage and data collected from 701 community participants to triangulate prevalence information.

Each year in Australia one in five adults is thought to experience a mental illness (Australian Bureau of Statistics, 1997) and across the lifetime one in four will be affected by a mental disorder (World Health Organization,

RESULTS

According to population estimates, 23.3% of all children in Australia have a parent with a non-substance mental illness, 20.4% of mental health service users have dependent children and 14.4% of the community study participants report having at least one parent with a mental illness.

CLINICAL IMPLICATIONS

The multiple prevalence estimates of the numbers of children in families with parental mental illness provide fundamental information for psychiatric policy, planning and programming.
2001. Given the mounting evidence that parental mental illness has a negative impact upon children (Cantwell & Baker, 1984; Beardslee et al, 1998; Klimes-Dougan et al, 1999; Mowbray & Mowbray, 2006; Mowbray et al, 2006) and the clear need for early intervention and prevention in this area, it is surprising that prevalence estimates of numbers of children in families with a parental mental illness have not been forthcoming. With the growing emphasis on policy and programmes in this area (James et al, 2007), this has not been forthcoming. With the growing emphasis on policy and programmes in this area (James et al, 2007), this study sought to provide multiple estimates of the numbers of Victorian and Australian children living in families where a parent has a mental illness. Such estimates would provide important information to policy and programme developers.

Australian policy and planning

Currently, Australian policy and planning relies upon US data (Nicholson et al, 2002) and/or small-scale Australian estimates extrapolated from adult in-patient mental health facilities (Farrell et al, 1999; Hare et al, 1999; Handley et al, 2001). In the USA, Nicholson et al (2002) found 68% of women and 54.5% of men with a non-substance psychiatric disorder slightly more likely to be parents than those without a psychiatric disorder (62.4% and 52.9% respectively). Unfortunately, this study focused on parents not children, did not differentiate between dependent and adult children and included single illness episodes across the life span, including those occurring before the children were born. For example, the parents’ average age at onset of psychiatric disorder was 4 years before their average age at the birth of the first child (Nicholson et al, 2002). Nevertheless, this work was extremely important as it highlighted that US federal policies and programmes should explicitly acknowledge parenthood in mental illness, suggested that a large number of children were living in households where at least one of the parents had a mental illness and noted the feasibility of a large number of future policies and programmes for both parents and children (Nicholson et al, 2002).

In Australia, several small-scale studies have made population estimates based on the proportion of service users with children undergoing treatment at a mental health facility (Hare et al, 1999; Handley et al, 2001). The Australian Infant, Child, Adolescent and Family Mental Health Association (2001) summarised these estimates by suggesting that between 29 and 35% of adult mental health service users were women with children under the age of 18 years. This is a much lower estimate of parent status compared with that of Nicholson et al’s (2002), although it should be noted that the Australian studies were based on small numbers of in-patients. Once again the number of children with parents who have had mental illness was not mentioned in the estimate.

Method

We used three methods to provide multiple prevalence perspectives. First, we combined the Australian Bureau of Statistics (ABS) mental health studies (Australian Bureau of Statistics, 1997) with family characteristics studies (Australian Bureau of Statistics, 2003a) to establish a population estimate. The second approach used records of all mental health service users in the state of Victoria during the 2003–2004 financial year. These service users are commonly considered to have a severely disabling mental illness (Victorian Mental Health Branch, personal communication, 2005 – one of the branch staff indicated that “the constitution of our clients is actually a mixture of “acute” and “chronic” cases”). The final approach used data from a moderately large general community survey of families with children 8–12 years old where parents self-identified their own and their spouse’s mental health status (Maybery et al, 2006). We then extrapolated the data using ABS, Victorian, and Australian population estimates (i.e. Victorian mental health attendees were extrapolated to the make Australian population estimates) to allow comparisons between the three approaches.

Population estimate

The population estimate relied upon cross-calculations employing the ABS Mental Health and Wellbeing: Profile of Adults, Australia (1997) and the Family Characteristics Australia (2003a) reports. Both studies involved multi-stage surveys conducted by the ABS that drew upon Australian representative samples of private households, with age and gender characteristics weighted to match the national census. The mental health survey sampled 13,624 private households and had 10,641 respondents (78.1% response rate). Volunteers responded to prevalence and severity of mental disorder questions in the past 12 months. The Family Characteristics report provided information on numbers of children and type of households in Australia and Victoria in 2003 and was conducted as a supplement to the monthly Australian labour force survey (Australian Bureau of Statistics, 2003b) of approximately 30,000 (0.4%) of Australian households. Sample data from both studies were extrapolated by the ABS using Australian demographic statistics to estimate the mental health and family characteristics of the entire Australian population.

Mental health service users in Victoria

The service usage of the 38,455 adults attending Victorian mental health services during the 2003–2004 financial year included 91.4% of users aged 20–60 years with most (67%) between 20 and 44 years old; 48% were female; 22% were hospitalised owing to their illness during this period.

Data from the community study

The third data-set was collected as part of a relatively large (n=701) community study (a normative study for comparison purposes in an evaluation of a programme for children in families with a parental mental illness) (Maybery et al, 2006). The study targeted, through
schools, both parents and their 8 to 12-year-old children from three Australian states. The parents self-identified their mental health status by responding to a yes/no question: ‘Have you (or your partner) ever been diagnosed with a mental illness?’ A great majority of parent respondents (90%) were female.

Results

The Australian Bureau of Statistics (1997) estimates that 12.5% of Australians experience a mental illness (excluding substance misuse-related mental illness and schizophrenia) during any 12-month period. Schizophrenia prevalence was included here based on estimates by Jablensky et al (2000), subsequently raising the figure to 12.9%. In terms of family characteristics, as the likelihood of having a parent with a mental illness is doubled in children with two parents, separate calculations were undertaken for one- and two-parent Australian families (542 600 and 1967 000 families respectively) (Australian Bureau of Statistics, 2003a). Two-parent families include the intact, step, blended and other classifications of families, as in the family characteristics report (Australian Bureau of Statistics, 2003a). Similar calculations were undertaken for the state of Victoria. The combined families and children totals are shown in Table 1, along with the 23.28% prevalence ratio across the different family types.

The data from the Victorian Mental Health Branch indicate that 7829 (20.4%) of the total 38 455 mental health service users for the year 2003–2004 were living with dependent children (Table 1; data were not available for the total number of children with parents with a mental illness and so do not include children not living with the parent). This is also extrapolated to the whole Australian population estimate.

Of the 701 parent participants in the community study, 83 responded (11.8%) that they had had a mental illness. In addition, 26 (3%) of participants responded that their spouse had had a mental illness. In total, in 101 (14.4%) of the families surveyed, at least one parent had a mental illness and a number of children had two parents with a mental illness. Although we recognise that in at least some families both parents would have a mental illness, such calculations were outside the scope of this paper.

Discussion

The three sets of data show different ‘snapshots’ of prevalence of children living in families with a parental mental illness. Multiple estimation allows triangulation of data from various sources. These diverse estimates make important additions to previous suggestions that approximately 30% of the Australian female mental health service users and 68% and 54% of US women and men with psychiatric disorders during their lifetime have dependent children (Australian Infant, Child, Adolescent and Family Mental Health Association, 2001; Nicholson et al, 2002).

Importantly, we focused on numbers of children and families rather than only parenthood. Perhaps more important is the illustration of numbers from three diverse perspectives including a large-scale population estimate, actual mental health facility usage and a general community sample. Together, these different sources provide valuable planning information for government policy and interventions, as well as important information to community agencies regarding the issue of parental mental illness. The data about families and children in our study challenge psychiatric service providers to acknowledge the large number of children and families in their prevention, early intervention and mental health treatment policies.

Interestingly, there is a large divergence in estimates of the number of children in families with parental mental illness in the general population (23.3%; 1 million Australian and 250 000 Victorian) (Australian Bureau of Statistics, 2003a) and in Victoria (1.3%; 60 000 estimated Australian and 14 403 Victorian) (Maybery et al, 2006). This can largely be explained by illness severity – all of the Victorian mental health service users could be considered to have a severely disabling mental illness compared with only 12.8% of those with a mental illness in Australia (the survey used multiple levels of illness disability; Australian Bureau of Statistics, 1997). Consequently, when illness severity is considered, the ABS estimate is much more comparable to the actual Victorian data. Together, these findings provide important information showing a broad picture estimate of all children in families with parental mental illness (i.e. 23.3% when not constrained by level of mental illness) and much smaller numbers (1.3%) where the illness is severe.

### Table 1. Australian and Victorian families and children living in families with at least one parent who has had a mental illness

<table>
<thead>
<tr>
<th>Data source</th>
<th>Percentage of total population</th>
<th>Australia, n</th>
<th>Victoria, n</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Families</td>
<td>Children</td>
</tr>
<tr>
<td>12.9% ABS</td>
<td>23.3</td>
<td>577 507</td>
<td>1 082 403</td>
</tr>
<tr>
<td>20.4% VMH</td>
<td>1.3</td>
<td>32 254(^1)</td>
<td>59 325(^2)</td>
</tr>
<tr>
<td>Cross-sectional study</td>
<td>14.4</td>
<td>361 382</td>
<td>668 462</td>
</tr>
<tr>
<td>Total</td>
<td>100.0</td>
<td>2 509 600</td>
<td>4 642 100</td>
</tr>
</tbody>
</table>


1. Estimate based on VMH actual data.
2. The ABS ratio (1.8743) of children:family was used to calculate the number of children for the VMH estimate.
Unfortunately, although parental mental illness does not in itself guarantee poor outcomes for children, more severe parent disability has been associated with less sensitive and competent parenting (Rogosch et al, 1992), significantly greater mental illness in offspring (Warner et al, 1995), insecure infant attachment (Teti et al, 1995; Frankel & Harmon, 1996) and lower quality of the mother–child relationship (Harnish et al, 1995). The estimate of just under 60,000 children living with a parent with a severe mental illness in Australia is likely to be very accurate as the figures are extrapolated to the Australian context from the 14,403 children of Victorian parents with a severe mental illness. This suggests a large number of children likely to be at risk owing to their parents’ severe mental illness.

The third estimation of prevalence simply involved asking a general community sample of parents of children aged 8–12 years whether they or their partner had had a mental illness. The resulting prevalence of 14.4% was considerably lower than the 23.3% from the ABS study. The discrepancy might be partly explained by differences in survey methods (i.e. respondents replied to a single question regarding previous illness diagnosis, whereas the ABS used a diagnostic questionnaire to determine mental health status), but this still equates to 668,462 children and 163,267 families in Australia.

Limitations

Although our findings provide valuable information about children of parents with a mental illness, there are several qualifiers. The ABS estimates have limitations as they are simply extrapolations from previous Australian mental health and family unit research. For example, it has been suggested that people with mental illnesses have more children than those without an illness (Nicholson et al, 2002), but other cross-calculations such as procreation differences in families with one and two-parent illness are largely unknown. In addition, the ABS 1997 and 2003 data-sets assume equivalence of population characteristics (i.e., that family and mental health characteristics remain consistent over time). Changes in such areas as migration patterns (e.g., fewer refugees with post-traumatic stress disorder or more professional families) may alter population characteristics and subsequent extrapolations using the different years may be less accurate. Future prevalence estimates should aim to use data from the same year. Alternatively, it is difficult to dispute the actual mental health service usage data from the state of Victoria. However, the third cross-sectional data source provided no information about age at onset or level of disability and was a self-estimation rather than a diagnosis by clinician interview. Furthermore, the data were obtained almost solely from female participants. A large ABS study similar to the Mental Health and Wellbeing Profile of Adults (1997) study, but focusing on family structures, would rectify the deficits in the data.

Notwithstanding the methodological problems, the multiple estimation procedures provide rudimentary prevalence information from a number of perspectives. The multisource data provide direction and evidence to support future psychiatric policy and practitioner decision-making (e.g., development and referrals to programmes) for children from families with a parental mental illness. This provides basic evidence to governments and mental health support agencies of a large number of children, many of whom could be considered to be living in a high-risk family environment. Multiple factors concerning the parent, such as diagnosis, illness chronicity and severity, social isolation, level of family support and financial stress, will differentially have impact on children, and the considerable number of children in such families should make them a high-priority group for future psychiatric decision-making regarding intervention and policy.

Acknowledgements

Thank you for the financial support of the Victorian Health Promotion Foundation (VicHealth), assistance from Phil Barelli and Francis Kung from Mental Health Branch Victoria (Department of Human Services), and feedback on an earlier draft of the paper from Elizabeth Fudge, Children of Parents with a Mental Illness Initiative.

References


AUSTRALIAN BUREAU OF STATISTICS (1997) Mental Health and Wellbeing: Profile of Adults, Australia. ABS.

AUSTRALIAN BUREAU OF STATISTICS (2003a) Family Characteristics, Australia. ABS.

AUSTRALIAN BUREAU OF STATISTICS (2003b) Labour Force, Australia. ABS.


*Darryl Maybery Senior Lecturer, School of Humanities and Social Sciences, Charles Sturt University, Wagga Wagga, Australia, email: dmowbray@csu.edu.au. Andrea Reupert Lecturer, School of Education, Charles Sturt University, Kent Patrick Lecturer, School of Humanities and Social Sciences, Charles Sturt University, and Melinda Goodyear Adjunct Lecturer, School of Humanities and Social Sciences, Charles Sturt University, Lin Crase Associate Professor and Head of Campus, LaTrobe University, Australia.

Problems across care pathways in specialist adult eating disorder services

AIMS AND METHOD

Despite considerable knowledge of outcomes for patients who complete treatment for eating disorders, less is known about earlier stages in the treatment journey. This study aimed to map the efficiency of the anticipated patient journey along care pathways. Referrals to specialist eating disorder services ($n=1887$) were tracked through the process of referral, assessment, treatment and discharge.

RESULTS

The patient mortality rate was low. However, there were serious problems of attrition throughout the care pathways. Of the original referrals where a meaningful conclusion could be reached, in approximately 35% the person was never seen, only half entered treatment and only a quarter reached the end of treatment.

CLINICAL IMPLICATIONS

This study demonstrates considerable inefficiency of resource utilisation. Suggestions are made for reducing this inefficiency, to allow more patients the opportunity of evidence-based care.

Method

The study was carried out in two highly specialised adult eating disorder services in south London (local catchment area population about 2.7 million; tertiary care provision for a further population of about 3.8 million). Each service has a patient-centred model of care offering a range of therapeutic interventions, in line with clinical guidelines (National Institute for Health and Clinical Excellence, 2004). Patients were accepted from the age of 18 years upwards. Treatment duration for in-patients and day patients was determined individually, and transitions were arranged according to individual clinical criteria (e.g. weight stability and ability to travel for day-patient work). For most people treated as out-patients, the treatment guideline was about 20 sessions for cases of bulimia and about 40 sessions for anorexia.

Over the two calendar years of the study (2002–3), a total of 1887 referrals were made to the two services (87.1% from the services’ catchment areas, 12.9% from outside those areas). All information was gathered from