Acc 10/7/08

Submission No. 672
(Inq into better support for carers)

THE ROYAL
AUSTRALIAN AND NEW ZEALAND
COLLEGE OF PSYCHIATRISTS

Submission to the Inquiry into better support for carers
June 2008

Introduction

The Royal Australian and New Zealand College of Psychiatrists (RANZCP) is pleased to provide this submission to the Inquiry into better support for carers in order to assist in developing a better understanding of the needs of carers. The RANZCP welcomes an extensive, future-focussed and outcome-oriented review of the ongoing challenges facing carers and would be pleased to work with the House of Representatives Family and Community Committee and others in securing a better future for all carers. The College advocates that mental health and well-being is central to all aspects of providing better outcomes for carers and that any practical support measures and strategies cannot be achieved effectively without addressing the mental health needs and concerns of carers, especially those carers supporting people with a mental illness.

The Inquiry Terms of Reference and the Committee media release (14 May 2008) recognise the diverse range of challenges that carers face in their daily lives. It provides the scope to explore this critical issue especially in terms of considering carers' own support needs and recognises that carers have a greater propensity to develop mental health disorders when compared to the general population and that these also need to be addressed if we are to improve mental health outcomes in the future.

Recognising the scope of the task and potential positive outcomes for carers, the College would welcome the opportunity to engage in further consultation with the Committee, through focused face-to-face discussion independently and/or in conjunction with colleague health care professions, carers and consumers. This might include the College's Board of Professional and Community relations, which includes a number of psychiatrist, consumer and carer members that are passionate about this important issue.

The RANZCP is committed to working with Government and governing mental health bodies in addressing the needs of carers of people with a mental illness and the mental health needs of carers themselves.

If you would like to discuss this submission or aspects of the Committee's Inquiry further please contact either:

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Executive summary

The number of mental health carers in Australia is hard to quantify as many carers do not identify themselves as carers due to the significant stigma associated with mental illness. The nature of the care giving role is also not often understood by many professionals or by society. The practice of blaming families for contributing to, if not causing mental illness has not completely disappeared, though community awareness of mental illness is rising. The periodic nature of episodes of mental illness means that often carers do not meet the assessment criteria to be recognised as a carer. Carers Australia (2006) estimate that on average, mental health carers provide 104 hours of support and care for family members with a mental illness each week. This significant reliance on carers perpetuates the significant barriers faced by carers and is one of the fundamental problems within the current health and mental health systems.

The RANZCP is a lead professional organisation for the training and professional development of psychiatrists in Australia and New Zealand. The College is a leader amongst Australasian medical Colleges in developing partnerships with consumers and family and other carers in respect to excellence of service provision.

The RANZCP recognises the important role carers and family members play in the ongoing care and treatment of people with a mental illness. The College's Board of Professional and Community Relations (BPCR) includes consumer and carer representatives from a variety of backgrounds who contribute extensively to the development and management of RANZCP programs and activities, and works together with the community to promote mental health, reduce the impact of mental illness on families, improve care options and supports, and ensures that the rights of people with mental health concerns are heard by mental health professionals. These representatives have an average of over 25 years of experience as carers and in advocating for other carers and the greater inclusion of family in the treatment of those with a mental illness.

The College believes the Inquiry process is timely as the issues will be better dealt with before factors that could exacerbate the plight of carers worsens. Those drivers include social factors as well as the changing burden of disease, which has implications for the service needs of carers and their families especially those with a mental illness;

> "...23% of the total Australian adult population are affected by one or more mental disorders in any given year" and "that about 14% of children and young people (or 500,000 persons) are affected by mental disorders within any six month period" (various authors cited in Australian Government National Mental Health Report 2007 page 15).
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> "... the Australian Institute of Health and Welfare reported mental disorders to be the third leading cause of overall disease burden, accounting for 13% of total burden and 27% of total years lost due to disability. Mental disorders rank third after heart disease and cancer as the largest causes of illness-related burden in Australia. However, they represent the largest single cause of disability, accounting for nearly 30% of the burden of non-fatal disease" (Mathers, Vos and Stevenson cited in the Australian Government's National Mental Health Report 2007 page 16).

Projections also suggest the mental health related disease burden will grow markedly as a proportion of overall disease burden (Begg, 2008). Given the greater propensity for carers to develop a mental illness, and the projected increase in mental health disorders, this is likely to increase the strains of carers and families.

Population ageing also presents challenges in that more of the population will require care, including carers themselves. Carers own health can be compromised with the burdens of care, especially over prolonged periods of time and when self care can be difficult to balance with other care demands. Further, prolonged periods of care often compromises a person's financial situation and capacity to earn income, generate superannuation or retirement savings and so on, further heightening the stresses experienced by carers.

In light or these factors, it is crucial that the current Inquiry into the needs of carers are also linked to current policy review underway across government in relation to Social Inclusion, including homelessness and others.

Non-government organisations have performed a key role in educating and supporting carers and providing support services to those with mental health problems and in advocating for services to be more responsive and relevant to carers needs. In many cases this has meant individual carers taking on an important advocacy role for others as well as the caring they provide directly. More support should be given to the development and expansion of nongovernment organisations to assist carers access meaningful supports, and promote self help and consumer advocacy, through information provision and opportunities to participate in mental health service decision-making and funding.

The College supports the need to increase the understanding of the population in helping to manage their health and to enhance skills of primary health care trainees and providers to improve their capacity for assessment, diagnosis, treatment and referral of people with mental health disorders. Part of that understanding should be recognition of the services and benefits that carers provide and the implications for the broader community if they did not.

Key considerations

The RANZCP College advocates that explicit action be taken in key areas as outlined below.

1. The role, contribution and recognition of carers in society

General attitudes to mental illness and mental health issues complicate the impact of mental illness on families and carers. They add to the existing social exclusion and pressures faced by carers on a daily basis. Most people are largely uneducated about the nature and effects of mental illness on the individual let alone carers, family members and friends. This situation needs to be redressed by disseminating information on the types and effects of mental illness, the prevalence of mental illness in the wider community, together with the variety of treatment methods available. Strategies that focus on prevention, better management and enhanced community awareness will further assist in reducing the stigma associated with mental illness and carers seeking help.

The reality is that mental illness is difficult to understand and often generates fear and considerable stigmatisation for the consumer and their family. It is often seen as being in the "too hard basket" by many in the service system and the greater community. Consequently, social support structures such as housing, rehabilitation, justice systems, income support arrangements, employment assistance etc all face particular difficulties and are often less effective in providing well tailored services and outcomes to people with mental illness. For carers, these difficulties and complexities are at least as great but the pressures they face in trying to deal with all of the issues and interactions can be extreme and unrelenting. As a result carers own health needs can suffer adversely and/or be overlooked.

As previously highlighted, evidence indicates that a significant proportion of family carers may go on to develop mental illness themselves as a result of burnout through the lack of recognition of what they do and the lack of accessible and relevant supports. A study conducted in Western Australia estimated that carers were 40% more likely to develop their own mental health problems than the general population. Where, alternatively, evidence indicates that an investment in family based interventions for mental illness that are founded on a best practice evidence base, would result in a 12% improvement in the patient's health status and are cost effective to implement (Vos, 2005). There are also a number of non-costed family generated interventions that provide meaningful long-term support to those with a mental illness that could be easily implemented with limited resource implications such as those suggested in the book

2. The barriers to social and economic participation for carers

Having a mental illness can affect basic abilities to think clearly, engage with others and work through bureaucratic processes. This adds to the difficulty in the person and their family in accessing appropriate services and supports on their behalf. Mental illness can interfere with the ability to work through administrative requirements, such as completing application forms or attending appointments and the capacity for independent living may fluctuate and be unpredictable. When a person is unwell, they may be heavily reliant on others to ensure the availability and coordination of support further impacting upon the carer's ability to actively participate in society.

Many people with mental illness are cared for in the community by "unpaid" carers or family members. Carers contain pressures on the health and other social support systems. Failure to recognise their contribution and needs exacerbates pressures on them leading to poorer personal health and compounding costs.

(a) The involvement of family carers in the care of their family members with severe disability from mental illness is complicated by legal, ethical, bureaucratic processes that are often complex and difficult to navigate and "cultural" issues. For instance, there may be confusing agendas between traditional ethical notions of confidentiality, privacy principles and legal obligations under the various State mental health acts. It is, however, noted that a duty to inform family is contained within Australian model mental health legislation and further enacted in some Mental Health Acts such as current NT legislation. While privacy is a valued right and needs to be protected it is imperative that other rights and responsibilities that protect the safety and quality of people's lives are also balanced in considerations. This is a complex area, but one that warrants review.

(b) Whilst it is recognised that governments and their agencies have been more sensitive to the needs of Aboriginal and Torres Strait Islander clients and Culturally and Linguistically Diverse (CALD) clients, more could be done to provide the same level of personalised services to people suffering from severe mental illness and their carers. As a result, the various criteria used by government agencies, e.g. Centrelink, to measure disability from severe mental illness may not be realistic and subsequently deny carers adequate support for the work that they do with family members. It is also recognised that it may be difficult for family carers to get respite, thus increasing the chance of carer burnout and the development of mental illness themselves.

(c) There may be a significant resistance to allow family carers flexibility within the workplace to allow time to care for their family members suffering from severe mental illness as needs arise. This may lead to loss of employment or hours of employment with subsequent loss of income, and self esteem, increasing the possibility for carer burnout. In addition, the episodic nature of mental illness can place further strain on the carer's own employment situation (where they are employed) with the consequent risk of losing employment and the broader individual costs associated with that. This also reduces the family and personal resources drawn on to enable the support family and others provide.

3. Key priority areas for action and practical measures to better support carers

Access to mental health services should be part of the range of support services available to carers, especially those caring for people with a mental illness. There is a significant amount of under-treatment for people with anxiety and depression, especially carers, which would require significant resourcing however would result in considerable improvements in health outcomes (Vos, 2005) and the burden of disease in society. Re-incorporation and co-location with general health services will achieve more decentralised mental health services closer to family, community and cultural networks and will reduce the stigma associated with seeking assistance for mental health concerns. A detailed analysis of the savings and cost-burden related to carers would help inform policymakers of the options and risks associated with increasing or not increasing the support available to carers.

Investment in family interventions for mental illness has been estimated to increase health outcomes by 12% for patients suffering specifically with schizophrenia, and when paired with more cost-effective treatment options has been estimated the potential to save approximately $30 million dollars to the Pharmaceutical Benefits Scheme each financial year in Australia (Vos, 2005).

Another key area of concern for carers of people with a mental illness relates to admissions to hospital for mental illness and the development of individual care plans that actively incorporate the carer or family member in the treatment of the patient from admission, including planning for discharge and following discharge. This happens in some situations but is far from uniform or common practice.

Although mental health professionals generally attempt to actively involve carers and family members in the treatment of their patients, greater facilitation of the process could possibly be achieved through a number of practical measures including:

- The development of practical guidelines that benchmark the level of professional standards the workforce should maintain especially within acute settings. The College is currently conducting a pilot project regarding the National Practice Standards for the Mental Health workforce and the learnings of this project could be implemented specifically in order to train and educate mental health workers about working more collaboratively with carers.
- The adaptation of professional guidelines (as above) that specifically address the particular needs of Indigenous and Culturally and Linguistically Diverse carers.
- The introduction of carer specific Medicare item numbers that would greater carer involvement (with the consent of the patient).

The College has a long standing history of developing clinical guidelines as well as practice guidelines for consumers and carers and would provide leadership and practical support in the development of these guidelines and the articulation of the standards into the mental health workforce.

4. Strategies to assist carers capacity building, transition in and out of the caring role and plan for the future.

Explicit recognition of family and others as carers supporting health service provision and outcomes is needed. The expressed preference for care in less institutional settings must ensure it is balanced with the provision of alternative support mechanisms. Community-based support for carers including improved crisis care and additional respite services should be expanded. This could be incorporated within the treatment regime of the person being cared for and for the benefit of the carer.

It is important to highlight that for many, transition out of the caring role only occurs with either the death of the person they are caring for or when the carer becomes incapacitated themselves through illness or mental illness. For mental health carers the transition out of the caring role is not a realistic goal for strategies to aim to achieve and this should be recognised. In terms of those carers that experience the loss of a family member, particularly under traumatic circumstances such as suicide, provisions should be made available to carers to access immediate support services so that they do not end up with a long-term mental illness themselves.

For many, the caring role starts early in childhood, caring for parents with a mental illness that carries through until their parents are elderly. All strategies need to address the different types of mental health carers in the context of the life stage of both the person with the mental illness and the mental health carer.

As previously highlighted, there are a number of existing strategies in place that actively support carers and an audit that includes a cost-benefit analysis of these programs or organisations should be conducted in order to determine the best strategy in moving forward. Well informed and supported consumers, carers and practitioners with adequate access to services and support will be better positioned to exercise their shared responsibilities and deliver the health and financial benefits sought.

Concluding remarks

Carers do not choose to become a carer of someone with a mental illness, nor does the person choose to develop the mental illness. The burden placed on mental health carers will only continue to increase if a number of integrated strategies are not developed and implemented in the immediate future and will further increase the burden of disease on the community. These practical measures should be targeted towards providing more supports to carers and towards systemic issues such as increased training for professional, research activities and benchmarks to reinforce appropriate standards and quality of care.

The College has a long history of working with and provide expert advice and guidance to carers and offers our leadership and practical support in the development and implementation of any initiatives that arise from this inquiry especially the development of these guidelines, and the articulation of the appropriate standards into the mental health workforce. The RANZCP is committed to working with Government and governing mental health bodies in addressing the crisis of mental health carers.

References

Begg, S.J., Vos, T., barker, B., Stanley, L. & Lopez, A.D. 2008, Burden of disease and injury in Australia in the new millennium: measuring health loss from diseases, injuries and risk factors, Medical Journal of Australia, Vol. 188, No. 1, pp. 36-40.

Carers Australia, 2006. *Final report: Carers of people with a Mental Illness Project*, Canberra: 17

Independent Living Centre of WA (Inc), 2006. *Family carers and the physical impact of Caring – Impact and Prevention research report*, Department for Community development, Western Australia: A2.

Johnson, D. Current issues in family research: can the burden of mental illness be relieved? In: Lefley HP, Wasow M. , editors. Helping families cope with mental illness. Chur: Harwood Academic Publishers; 1994. pp. 309–328.

Vos, T., Haby, M., Magnus, A., Mihalopoulos, C., Andrews, G. & Carter, R. 2005, 'Assessing cost-effectiveness in mental health: helping policy-makers prioritize and plan health services, Australian and New Zealand Journal of Psychiatry Vol 39, pp. 701- 712.

World Schizophrenia Fellowship, 1998. *Families as partners in care.*