EDITORIAL

Families and carers – their role

David Skuse

Behavioural and Brain Sciences Unit, Institute of Child Health, London, UK, email d.skuse@ich.ucl.ac.uk

This issue's thematic papers consider the role played by families and carers in the management of major mental illness and dementia. Within many countries with well developed health services, the former asylum system of care has been replaced by 'care in the community', but asylums are still widely used in low- and middle-income parts of the world. The convention of psychiatric care by doctors, with the attendant medical model of mental illness, has, though, become less prominent in the past 50 years. Besides a widening range of experts providing services to those with mental illness and dementia, there is a trend towards engaging patients themselves in their management, as well as their families and other carers. These issues are discussed by Javed and Herrman in the context of developing and sustaining partnerships with patients and carers to deliver better mental health services in both high-income and middle- and low-income countries. They point out that the World Health Organization supports this trend, as does the Royal College of Psychiatrists. There could be disadvantages though, and they acknowledge the possibility of there being an associated financial penalty to the families who are expected to provide that care.

In Arabic culture there is a long history, going back many centuries, of family obligation to sick relatives. Even when asylums were first established in the Arab world, in the 13th century, families were engaged in the care of people with mental illness, according to the article by Loza and Effat. This tradition began to change when Western powers came to exert their influence and introduced a different style of care, based on an institutionalised health service. Stigma towards people with a mental illness allegedly increased, as the distance from their communities grew and their prominence in their own communities decreased. The authors emphasise that, although care in the community has undoubted benefits, it brings with it a greater burden on those tasked with providing care, especially if there are few professional supports in place because of financial constraints.

Finally, we segue into the report from Chaaya and colleagues concerning families in Lebanon who are looking after a relative with dementia. As the proportion of elderly members in our population grows, so the number of those with dementia increases disproportionately. In Lebanon, the burden of care largely falls upon middle-aged daughters, who are consequently often unable to work outside the home, unless they employ paid staff. The financial and emotional stress on such family carers is considerable, and was measured objectively in this investigation.

While the aim of engaging patients and their families in discussions about their care, and the form of that care in the community, is laudable and influential, this theme emphasises that this new model of care has had unforeseen consequences. The financial burden and stress of providing such care must be acknowledged by mental health professionals and policy makers wherever it is introduced.

THEMATIC PAPER

Involving patients, carers and families: an international perspective on emerging priorities

Afzal Javed[1] and Helen Herrman[2]

[1]The Medical Centre, Manor Court Avenue, Nuneaton. UK, email afzal.javed@ntlworld.com

[2]Orygen, The National Centre of Excellence in Youth Mental Health, and Centre for Youth Mental Health, University of Melbourne, Australia; President Elect, World Psychiatric Association, email h.herrman@unimelb.edu.au

This paper focuses on the importance of involving patients, families and other carers when offering and deciding on treatment and care options. It highlights the activities of international and national organisations in facilitating collaboration with patients and families in treatment, research, teaching and training related to mental healthcare.

The treatment and care of a person living with mental illness require a comprehensive and evidence-based approach that includes support for the active participation of that patient and their family. The relationship among different stakeholders in this equation – patients, families and practitioners – is, however, perceived differently by each. The patients and their families often experience limited opportunity to offer information and have little power to influence decisions. Families and carers may feel isolated if left alone or not involved in the treatment of their loved ones. Practitioners sometimes feel ill equipped or unsupported, or lack the time to undertake this work. However, it is widely accepted that in order to improve services and care it is necessary to acknowledge the personal experiences of patients and of their families and friends, and to seek their inclusion in the planning and organising of care.

Historical context

Perceptions of psychiatry and mental health among professionals and general communities have changed significantly during the past century. There is strong evidence, however, that stigma, discrimination and failure to respect the human rights and dignity of people living with mental illnesses continue to exist all over the world (Collins *et al*, 2011). Until recent decades, in most countries a uni-professional approach to mental healthcare was dominant. Psychiatrists and big institutions were entrusted with the job of looking after patients with conditions recognised as mental illness in a protected environment. However, since the middle of the 20th century many other professionals, including psychologists, nurses, general physicians, occupational therapists, social workers, accommodation and employment workers, and advocacy services have become equal partners in providing health and social care. Although these trends are more evident in high-income countries, such ideas are also becoming more acceptable in low- and middle-income countries.

Another significant change is the growing acknowledgement within current practice of the need to involve the patients living with mental illnesses in their own care and treatment, as well as their families. The importance of patient empowerment and participation and of their human rights is increasingly recognised all over the world (Dhanda & Narayan, 2007; Sunkel, 2011). There is ample evidence that working with carers and families is not only beneficial for short-term outcomes but may also lead to long-lasting improvements in the mental health, function and quality of life of those with mental disorders. The literature documents the importance of developing and sustaining partnerships with patients and carers (Crawford *et al*, 2002).

Families were kept away from the care of psychiatric patients during the institutional era. Little attention was paid to the family's supporting and expert roles. The closure of the institutions that started in many countries during the second half of the 20th century, however, resulted in many individuals with mental illnesses returning to live with their families or elsewhere in the community. Since that time, families have been involved along with professionals in helping patients to ameliorate the impact of mental illness. A strong movement has brought families and carers on board (Campbell, 2009). There has also been a promising shift in understanding the influence of families. Families and carers are no longer held responsible for the onset of patients' problems. Instead, the mental illness and associated problems are now seen as arising from a combination of factors.

Empowerment

There is a growing interest in the movements supporting empowerment of patients and families. Their involvement is becoming a guiding principle in the UK, the USA, Australia and other countries. These changes are taking place with an understanding based on evidence and experience: that the development of patient and family groups and their active involvement in healthcare systems lead to more accessible and acceptable services and improvements in the quality of life of patients and families. This has been advocated by the World Health Organization (2001) and evidence is accumulating from the work of patient and family and carer groups in different parts of the world (Katantoka, 2007; Royal College of Psychiatrists, 2009; Royal Australian and New Zealand College of Psychiatrists, 2014).

Problems associated with caring roles

Family carers, however, often experience physical, psychological, social and financial problems as a consequence of caring for a relative. Stress, depression, anxiety and frustrations are common in the periods of acute care and for some they may continue for many years. A study conducted in Sri Lanka by an organisation called Basic Needs (Table 1) has shown that stigma, discrimination, exclusion, 'livelihood hardship' (economic burden) and difficulties in getting access to adequate treatment and care are salient features of the problems expressed by carers (Basic Needs, 2013). Families receive little recognition for their valuable work, and most countries, including high-income countries, fail to offer financial support for the care services that families provide.

Despite the significant evidence of benefits, the involvement of patients and families in mental health services remains patchy. There are a number of barriers to useful initiatives. These include carers' understanding of the illness and expectations of services. Conversely, the awareness, acceptance and acknowledgement from

Table 1

Common problems experienced by carers: numbers and proportions of survey respondents mentioning specific problems

	No. of respondents	Proportion of respondents
Stigma, discrimination and exclusion	71	33 %
Livelihood hardship/economic burden	33	15 %
Carers' burden	29	13 %
Problems related to the mental illness	29	13 %
Family relationships	17	8 %
Mental health service issues	16	7 %
Lack of rehabilitation	9	4 %

Findings from the study Organisation of Mental Health Service Users and Carers: A Mapping in Sri Lanka, conducted by Basic Needs 2012–13 (Basic Needs, 2013).

professionals and the competencies of many professional groups in dealing with these issues have also been noted as major barriers and are neglected in many places.

The work of national, regional and international organisations

Despite these limitations, a great deal of work has been accomplished by a number of national, regional and international organisations.

The World Psychiatric Association (WPA), the representative organisation of psychiatrists globally, has raised the profile of this aspect of care. During the 2008–11 triennium, the WPA appointed a task force that included service users and family carers and representatives from Europe, Africa and Asia to develop best practices for working with service users and carers. The task force provided a set of recommendations for the international mental health community and direction for the member societies of the WPA, for implementation in their respective countries (Wallcraft *et al*, 2011).

The World Association for Psychosocial Rehabilitation (WAPR), another organisation that works in the field of psychiatric rehabilitation, emphasises the roles of patients, carers and families in treatment and rehabilitation programmes worldwide (see http://www.wapr.org). The WAPR has established a standing task force that sets and reviews guidelines for future work in this area.

Several national and regional associations have taken a lead in giving importance to the work of patients and carers, including the Royal College of Psychiatrists in the UK and the Royal Australian and New Zealand College of Psychiatrists (RANZCP). The Royal College of Psychiatrists regularly invites local carers' and users' groups to contribute to the training programmes for psychiatrists. This strategy has increased the knowledge, awareness and responsiveness of the trainee psychiatrists at their workplaces. The College has also taken a number of initiatives in collaboration with the Princess Royal Trust for Carers, including an approach known as the 'triangle of care' developed by carers and the professionals to improve carers' engagement in treatment services. The guidelines supporting this approach outline key elements in achieving the partnership and give examples of good practice (Royal College of Psychiatrists, 2009); and they are supported by work from other organisations. The RANZCP has a Consumer and Care Committee that participates in governance of the College, including appointing service users and carers as members of the College Board. The RANZCP has developed guidelines for inclusive policy and practice (Royal Australian and New Zealand College of Psychiatrists, 2014).

The World Health Organization's (2013) Mental Health Action Plan 2013–20 was approved by all member states at the World Health Assembly in May 2013. It calls for more active involvement and support of service users in the reorganisation, delivery, evaluation and monitoring of services so that care and treatment become more responsive to their needs. The Plan also calls for greater collaboration with families and other 'informal' mental healthcare providers, such as religious leaders, faith healers, traditional healers, schoolteachers, police officers and local non-governmental organisations. The World Health Organization urges member states to:

> Integrate and coordinate holistic prevention, promotion, rehabilitation, care and support that aims at meeting both mental and physical health care needs and facilitates the recovery of persons of all ages with mental disorders within and across general health and social services (including the promotion of the right to employment, housing, and education) through service user-driven treatment and recovery plans and, where appropriate, with the inputs of families and carers. (World Health Organization, 2013, p. 15)

The Plan urges the World Health Organization to:

> Collate and disseminate evidence and best practices for the integration and multisectoral coordination of holistic care, emphasizing recovery and support needs for persons with mental disorders, including alternatives to coercive practices and strategies to engage service users, families and carers in service planning and treatment decisions. (World Health Organization, 2013, p. 16)

Several illustrative strategies for implementing the World Health Organization's Plan involve service users and carers. The leaders of treatment and care services should engage and collaborate with people with mental disorders, carers and family members, and should advocate effectively for increased resource allocation and the development and implementation of policies, laws and services relating to mental health. This is likely to mean formalised structures and mechanisms and may require the building of capacity and awareness among local groups about mental health, law and human rights, and their responsibilities in relation to these. Alongside this is the need for the empowerment of people with mental disorders and related disabilities and their organisations, and ensuring they have a formal role and authority to influence the design, planning and implementation of policies, laws and services.

Providing logistic, technical and financial support to organisations at local, national and international levels, and involving people with mental disorders and their families in the training of health workers, as peer support workers and in the inspection and monitoring of mental health services are all cited in the Plan as strategies to be considered.

Conclusions

Mental health problems lead to personal, family, social and economic adversities. The roles and responsibilities of professionals, patients, families and carers in responding to these problems through treatment and care, teaching, research and policy-making need to be acknowledged and respected in a more noticeable way. The policies that shape the responses should be based on social inclusion and the participation of patients, professionals and families, and should place emphasis on the rights of people with mental illness, as well as on fairness, equality and justice. The experience of caring for a family member with mental ill health may bring rewards, but it is also known across countries and cultures to increase the suffering of family members and to heighten their risk of a number of physical, psychological, social and financial problems. These results have led to a call for action at national and international levels to reduce the adverse effects on the families as well as those with lived experience of illness (Gonzalez *et al*, 2011; World Health Organization, 2013).

Research and future work need to focus on supporting the resilience of patients and families, and on examining their strengths and the factors that protect them. The long-term consequences of caregiving and the support, information and training essential to patients and families at various stages of an illness need to be understood in depth and appropriate empowerment and communication with services formalised. There is, equally, a strong need for mental health professionals to make a thorough assessment of patient and family members' strengths as well as their limitations. Mental health professionals must develop a reliable understanding of the needs of patients for respect, dignity and support during treatment and recovery. They need an equally good understanding of the resources that families have and do not have to support and live successfully with those who are mentally ill.

The continuing support of mental health professionals and policy makers and their positive attitudes towards patient and family participation in turn can give critical support to innovative programmes for patient, family and carer empowerment. Including patients and families as active members of healthcare teams and using their experiences by involving them as trainers and researchers can improve services as well as add support and ease their burdens (Simpson *et al*, 2002).

References

Basic Needs (2013) *Organizations of Mental Health Service Users and Carers: A Mapping in Sri Lanka Conducted by Basic Needs 2012–13*. Basic Needs.

Campbell, J. (2009) Methods. In *Handbook of Service User Involvement in Mental Health Research* (eds J. Wallcraft, B. Schrank & M. Amering), pp. 113–138. Wiley-Blackwell.

Collins, P. Y., Patel, V., Joestl, S. S., *et al* (2011) Grand challenges in global mental health. *Nature*, **475 (7354)**, 27–30.

Crawford, M. J., Rutter, D., Manley, C., *et al* (2002) Systematic review of involving patients in the planning and development of health care. *BMJ*, **325**, 1263–1265.

Dhanda, A. & Narayan, T. (2007) Mental health and human rights. *Lancet*, **370**, 1198–1199.

Gonzalez, E. W., Polansky, M., Lippa, C. F., *et al* (2011) Family caregivers at risk: who are they? *Issues in Mental Health Nursing*, **32**, 528–536.

Katantoka, S. (2007) Users' networks for Africans with mental disorders. *Lancet*, **370**, 919–920.

Royal Australian and New Zealand College of Psychiatrists (2014) *Consumer, Family/Whānau and Carer Engagement*, Position Statement 62. Available at https://www.ranzcp.org/Files/Resources/College_Statements/Position_Statements/PS-62-PPC-Consumer-and-Carer-Engagement.aspx (accessed January 2016).

Royal College of Psychiatrists (2009) *Mental Health and Social Inclusion*, Position Statement PS01/2009. RCPsych.

Simpson, E. L., House, A. O. & Barkham, M. (2002) *A Guide to Involving Users, Ex-users and Carers in Mental Health Service Planning, Delivery or Research: A Health Technology Approach*. Academic Unit of Psychiatry and Behavioural Sciences, University of Leeds.

Sunkel, S. (2011) Empowerment and partnership in mental health. *Lancet*, **379**, 201–202

Wallcraft, J., Amering, M., Freidin, J., *et al* (2011) Partnerships for better mental health worldwide: WPA recommendations on best practices in working with service users and family carers. *World Psychiatry*, **10**, 229–236.

World Health Organization (2001) *Mental Health: New Understanding, New Hope*. *World Health Report*. WHO.

World Health Organization (2013) *Mental Health Action Plan 2013–2020*. WHO.

THEMATIC PAPER

Service users and carers in low- and middle-income countries

Nasser Loza[1] and Randa Effat[2]

[1]The Behman Hospital, Cairo, Egypt, email nloza@behman.com

[2]The Behman Hospital, Cairo, Egypt, email rkeffat@aucegypt.edu

Taking the Middle East as an example, we explore ways to empower service users and carers. Resources are required for the introduction of community mental health systems and the development of tailor-made psychoeducation, both of which need to be culturally and historically sensitive. A further aim should be the sustained and constructive engagement of families in caring for relatives who have a mental illness, in the community.

Background

Traditional societies around the world have looked after people who are mentally ill in their communities and families. Some religious cultures believe in the spiritual abilities of individuals with mental illness. It was therefore usual to show kindness and generosity to community members with mental symptoms.

The first psychiatric hospitals in the world were established in the 13th century in the Middle East. Departments of mental health were present in