

the person receiving care, with a focus on in-patient care and experiences of physical and chemical restraint. They include the results of a recent survey that gives a troubling snapshot of the ongoing issues in British mental healthcare today. While practices in British psychiatry may be less dangerous and less overtly coercive than elsewhere, it is clear that many patients are traumatised by their experiences. The article concludes by looking at some remedies that could improve the experience of in-patient care in general and reduce the use of coercive measures in particular, such as alterations to rigid daily routines, improved communication and co-production on wards. While containment is sometimes unavoidable for safety reasons and the 'least bad' course of action, any measures to reduce the need for it must be welcome.

The third paper, authored from three continents, attempts to draw together some of the key international themes regarding coercion. It focuses on societal structures, individual beliefs, the lack of legislation or lack of enforcement of it, and the crucial role of economic factors.

There is such scale, diversity and complexity that it seems almost impossible to find a way through. However, the same was undoubtedly true of apartheid (who can forget those newsreels from the townships in the 1980s?), racial discrimination and homophobia. With all these, significant progress is being made. In mental healthcare, too, there are things that can undoubtedly be done to begin to change things and specific remedies that can help. Recently a major pharmaceutical company announced that it will be relaxing its patents to allow poorer countries to manufacture and use its products cheaply (GlaxoSmithKline, 2016). If other companies acted similarly, this could lead to a significant increase in the availability of effective modern medications in poorer countries,

which could reduce distress and burden for a large number of people. Many low-income countries are implementing legislation and have ratified the United Nations Convention on the Rights of Persons with Disabilities. Service user groups in many countries have increasingly powerful voices. Our knowledge of what works and what does not work in terms of treatment is improving. Crucially, more governments are waking up and realising the waste of human potential that this neglect of mental healthcare and ongoing exclusion and coercion represent. On a global scale, such abuses represent a stain on societies and an unnecessary economic waste. On an individual level they must be a tragedy beyond words – for the person and for the family. The photographs and descriptions in the HRW report make this clear. I hope that in 20 years my daughters (among others) will be talking to their utterly incredulous children about how people with mental health problems used to be chained up – wouldn't that be something worth making changes for?

References

Alem, A. & Manning, C. (2016) Africa. In *Coercion in Community Mental Health Care: International Perspectives* (eds A. Molodynski, J. Rugkåsa & T. Burns), pp. 301–315. Oxford University Press.

GlaxoSmithKline (2016) Press release, 'GSK expands graduated approach to patents and intellectual property to widen access to medicines in the world's poorest countries'. Available at <https://us.gsk.com/en-us/media/press-releases/2016/gsk-expands-graduated-approach-to-patents-and-intellectual-property-to-widen-access-to-medicines-in-the-world-s-poorest-countries> (accessed 19 October 2016).

Human Rights Watch (2016) *Living in Hell. Abuses Against People with Psychosocial Disabilities in Indonesia*. Available at <https://www.hrw.org/report/2016/03/21/living-hell/abuses-against-people-psycho-social-disabilities-indonesia> (accessed 19 October 2016).

Molodynski, A., Rugkåsa, J. & Burns, T. (eds) (2016) *Coercion in Community Mental Health Care: International Perspectives*. Oxford University Press.

THEMATIC
PAPER

Mental health, coercion and family caregiving: issues from the international literature

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This article summarises current knowledge about two aspects of family care for people with mental illness: potentially pressurising or coercive aspects of family life; and family carers' experiences of being involved in coercive service interventions. There is a paucity of studies on these topics, especially outside Europe, North America and Australasia, and further research is recommended.

Caregiving within families forms part of normative cultural expectations everywhere. In many parts of the world, where health systems are non-existent or limited, family members may be the sole source of help for people with mental illness. Where services do exist, family members are often involved in delivery. Their role is increasingly written into mental health policy and law, which often specify a role for caregivers in compulsory

Note that, due to limitations on space, only select references are cited and listed in this article; further references are available from the authors on request.

treatment (Rugkåsa, 2016). While there are some studies reporting family caregivers' experiences of involvement in compulsion, there is almost a complete lack of research investigating how they exert influence when helping a relative with medication, finance, housing and other issues. There is a dearth of published research on caregiving, pressure and coercion from outside Europe, North America and Australasia (Rugkåsa, 2016).

In this article we summarise current knowledge about two aspects to family caregiving and pressure on people with mental illness. First, we highlight some potentially pressurising or coercive aspects of family life. Second, we summarise studies of family caregivers' experiences of involvement in coercive treatment of their relative. Although our focus is on pressure and coercion, it is important to note that this is but one dimension to the irreplaceable contribution most family caregivers make (often to their own detriment) and which is motivated by love, identity and compassion, as well as frustrations, sadness and fear, and a deep desire to help their relative to recover.

Potentially pressurising aspects of family care

Caregivers' support of their unwell relative has the potential to influence or coerce, or to be perceived as such, regardless of their intention. For example, caregivers may try hard to get reluctant patients to engage in social interactions or activities that the caregiver believes will improve their general wellbeing (Villatoro & Aneshensel, 2014). Caregivers may sometimes consider it necessary to take control over matters often considered to be private, such as finances and medication.

Caregivers' interactions with their unwell relative are shaped by their cultural models for what mental illness is and how it should be treated, and for the obligations family members have to support one another. For example, how one deals with the universal stigmatisation of mental illness varies. Stigma may have implications for both the patient's and the entire family's employment opportunities, status, honour or marriage prospects (Shefer *et al.*, 2013). As protection, some families may conceal the illness or hide away the unwell relative (Shefer *et al.*, 2013). This may delay presentation to services (Villatoro & Aneshensel, 2014).

Other sociocultural factors also influence help-seeking. Those who perceive mental illness as resulting from witchcraft, spirit possession or misconduct by the person with the condition (or even the misconduct of a relative of an earlier generation) may seek supernatural solutions, sometimes with the support of mental health professionals. Those with a strong belief in pharmaceutical solutions may encourage patients to seek psychiatric help. Often, people alternate between traditional and biomedical services, and family pressure can lead a relative with mental illness either towards or away from particular treatment approaches (Villatoro & Aneshensel, 2014).

Coercion by family caregivers

People with acute mental illness may reject support, neglect themselves, damage relationships, mismanage their finances, or endanger the health and safety of either themselves or others. To prevent these harmful outcomes, family caregivers may try to apply different forms of control. A range of techniques to ensure their relative takes medication are described in the literature, from collecting medication and reminding their relative to take it, to bringing them to clinics or administering pills directly. Surreptitious administration of medication (e.g. in food or drink) by caregivers has also been reported (Hallam, 2007) and is even supervised by psychiatrists in some places (Shah & Basu, 2010). Also, caregivers may make implicit or explicit threats to contact the police or the hospital in order to make patients adhere to treatment, especially when acutely ill.

There are reports of people with mental illness being restrained or confined in the family home either by shackles or by being locked into a room or specially designed hut, sometimes for years. Much attention is given to the practice of *pasung* in Indonesia but similar practices exist elsewhere (Guan *et al.*, 2015). Usually described as a measure of desperation due to poverty or a lack of services, there is a paucity of studies exploring such practices from the viewpoint of family caregivers themselves. One ethnographic study from Indonesia demonstrates the complexity of these practices (Tyas, 2010). Family members describe *pasung* as resulting from psychiatric services being geographically or financially inaccessible, or as the treatment recommended to them by elders or religious faith healers. It is also a means of protecting patients against abuse on psychiatric wards, or against violence, stigma or humiliation in the community. While sometimes seen as the only option by caregivers, it causes some of them to feel guilt, regret and sadness. Local services seem well aware of the practice and some patients are visited regularly by community nurses.

Caregiver involvement in coercive service delivery

The ways in which family members are involved in mental health services vary. In many places, professionals are explicitly encouraged to view families as integral to healthcare systems. This can work well, sometimes creating real partnerships. In systems where medical records are not in regular use, for example, psychiatrists often depend on the family to obtain information, which can give relatives extensive influence on clinical decision-making (Nunley, 1988).

A fairly substantial literature demonstrates difficulties in achieving proper caregiver involvement, however (Eassom *et al.*, 2014). Caregivers' expertise is often reported as going unrecognised despite their intimate knowledge of a patient's circumstances and changing needs (Jankovic *et al.*, 2011). A great deal of conflict emerges from patients' rights to confidentiality, on the one hand,

and caregivers' wishes to be involved and to help, on the other. Some have suggested that if services found ways around issues of confidentiality, caregivers' involvement could reduce the need for coercive treatment (Nurjannah *et al.*, 2014).

In-patient coercion

The Western concern with patient confidentiality is not necessarily shared by other traditions (Shah & Basu, 2010). In many parts of India, for example, it is required that a family member resides with a hospitalised patient to ensure the patient remains in hospital, to cook for them, to assist with personal hygiene and to provide clinicians with information, and this role takes precedence over issues of patient confidentiality (Nunley, 1988).

Most mental health laws have provision for family members to apply for legal compulsion. Initiating involuntary hospitalisation is usually described by caregivers as a last resort, and as humiliating and painful for everyone. Their involvement with legal coercion can sometimes place them in adversarial positions vis-à-vis the patient, which can make some caregivers reluctant to seek help. Even so, hospitalisation can represent an essential 'safety net' or respite (Hallam, 2007) for caregivers during crises.

Coercive community interventions

Family caregivers are often closely involved in out-patient care, frequently ensuring that patients adhere to medication. In general, they seem to welcome community-based services with assertive delivery models or formal out-patient compulsion in the form of community treatment orders (CTOs) if this means improved care. Many caregivers hope that a CTO can prevent their relative from fully relapsing before services intervene (Ridley *et al.*, 2010). Also, the authority of mental health professionals or the law can remove some of the risk of damage to relationships which can exist when caregivers monitor medication and finances.

Caregivers' experiences of CTOs are mixed, however. For some, CTOs have led to increased involvement and influence over decisions (Hallam, 2007) and better patient care (Ridley *et al.*, 2010), but others report a lack of consultation and involvement (Canvin *et al.*, 2014). Some say demands on beds mean that patients can be discharged onto CTOs prematurely with an expectation that relatives are ready and able to look after them (Hallam, 2007). Some caregivers are concerned that CTOs are too narrowly focused on medication and fail to help people to live better lives and to recover (Canvin *et al.*, 2014).

Conclusions

That family members try to influence each other is not surprising: it is a universal feature of family life. However, caring for a relative with severe mental illness, who is difficult to control or whose treatment is enforced by law, may transform the nature or meaning of family dynamics. Interpretations of mental illness and its cure are inevitably

made in light of culturally available explanations and occur in contexts of variable access to psychiatric services and financial resources. Regardless of intentions, some caregivers' approaches may be pressurising or coercive, and can amount to deprivation of liberty.

Family caregivers may also cooperate with coercive services (although they sometimes oppose them). While many feel excluded from decision-making, caregivers generally value the opportunity to be involved and generally want more influence. Improved carer involvement may reduce the use of coercion, but it is important to note that some family carers prefer to have less care responsibility for their relative. Some judge, however, that the absence or inadequacy of services makes it unsafe for them to take a step back.

Current evidence regarding the role of family carers in the coercion of people with mental illness is scarce, and the scope and quality of studies vary greatly. We particularly need further research from countries where formal health services or mental health legislation are lacking or in development in order to facilitate comparative studies of this complex and important issue.

References

- Canvin, K., Rugkása, J., Sinclair, J., *et al.* (2014) Patient, psychiatrist and family carer experiences of community treatment orders: qualitative study. *Social Psychiatry and Psychiatric Epidemiology*, *49*, 1873–1882.
- Eassom, E., Giacco, D., Dirik, A., *et al.* (2014) Implementing family involvement in the treatment of patients with psychosis: a systematic review of facilitating and hindering factors. *BMJ Open*, *4*, e006108.
- Guan, L., Liu, J., Wu, X. M., *et al.* (2015) Unlocking patients with mental disorders who were in restraints at home: a national follow-up study of China's new public mental health initiatives. *PLoS One*, *10*, e0121425.
- Hallam, L. (2007) How involuntary commitment impacts on the burden of care of the family. *International Journal of Mental Health Nursing*, *16*, 247–256.
- Jankovic, J., Yeeles, K., Katsakou, C., *et al.* (2011) Family caregivers' experiences of involuntary psychiatric hospital admissions of their relatives – a qualitative study. *PLoS One*, *6*, e25425.
- Nunley, M. (1988) The involvement of families in Indian psychiatry. *Culture, Medicine and Psychiatry*, *22*, 317–353.
- Nurjannah, I., Mills, J., Usher, K., *et al.* (2014) Discharge planning in mental health care: an integrative review of the literature. *Journal of Clinical Nursing*, *23*, 1175–1185.
- Ridley, J., Hunter, S. & Rosengard, A. (2010) Partners in care? Views and experiences of carers from a cohort study of the early implementation of the Mental Health (Care & Treatment) (Scotland) Act 2003. *Health and Social Care in the Community*, *18*, 474–482.
- Rugkása, J. (2016) Family carers and coercion in the community. In *Coercion in Community Mental Health Care: International Perspectives* (eds A. Molodynski, J. Rugkása & T. Burns), pp. 161–178. Oxford University Press.
- Shah, R. & Basu, D. (2010) Coercion in psychiatric care: global and Indian perspective. *Indian Journal of Psychiatry*, *52*, 203–206.
- Shefer, G., Rose, D., Nellums, L., *et al.* (2013) 'Our community is the worst': the influence of cultural beliefs on stigma, relationships with family and help-seeking in three ethnic communities in London. *International Journal of Social Psychiatry*, *59*, 535–544.
- Tyas, T. H. (2010) *Pasung: Family Experience of Dealing with 'the Deviant' in Nanggroe Aceh Darussalam, Indonesia*. Lap Lambert Academic Publishing.
- Villatoro, A. P. & Aneshensel, C. S. (2014) Family influences on the use of mental health services among African Americans. *Journal of Health and Social Behavior*, *55*, 161–180.