

Community care for people with mental illness: challenges emerging in the 2020s and consequent recommendations

The later years of the 20th and the beginning of the 21st century – coinciding with deinstitutionalization and shift to managing mental health problems outside of hospitals – have been characterized by several socioeconomic trends which are of major importance for the strategies of community mental health care^{1,2}.

The rampant urbanization is one of these trends. All the predictions are in agreement that at least 60% of the world's population will live in towns by the year 2050. Urbanization has many positive effects, but it also affects the notion of community. The increasing population density, combined with the lack of links or relations between neighbours, reduces their tolerance for behaviour which was previously not seen as disturbing.

Another trend which is relevant to community psychiatry is commodification, i.e., the tendency to measure everything in financial terms of losses and gains. The conversion of health care from being society's ethical obligation to being an economic opportunity has led to an increase of privately owned health care institutions and other services. It is also leading to a neglect of care for those who are poor and unemployed. Private health care facilities attract the best specialists by offering high salaries, which leaves government health services with lesser chances to employ the best of staff. It also makes it more difficult to organize health care in the community.

The tremendous development of social media is also contributing to the obsolescence of the concept of geographically defined communities. At the same time, the poor, the elderly and other people who do not use social media are becoming even more separated from those who do, although they live in the same locality or close to those who have access to the tools of the Internet age and the skills to use them.

The developments in low- and middle-income countries should be an even greater reason for concern. In many countries, rich people have withdrawn into gated settings, sometimes protected by barbed wire fences from the rest of the population. The fact that they live in the same geographical area rarely makes them interested or ready to help others. Those making up the middle class and the poor live more and more often in high rise dwellings making contact and mutual help less likely or impossible. The poor in favelas and other forms of slum have more contact and often help one another – conditions in which they live make this necessary, not necessarily desired.

The disappearance of the community defined as a group of people knowing and helping one another has led to the replacement of the notion of *community care* by that of *care in the community*, meaning that the care is provided outside of a hospital or other inpatient facility rather than in collaboration with people living next to the person who is suffering from a disease. The only persons in the “community” are members of the family of the person who is not well, and more rarely friends of that person.

Most of the people with more severe forms of mental illness (unless they are rich and make use of private institutions) are left in the setting in which they lived before the illness broke out. They

are usually looked after by their families, for whom the responsibility to provide care can be a huge burden and an obstacle to provide education to children or live a life of acceptable quality. So, it has become necessary to re-examine the principles of care defined in the late years of the 20th century³, and produce plans which will help people who have mental illness and their families or others who provide care.

In my opinion, the following measures – partly recommended by health care authorities and experts and by representatives of families and other carers – will have to be introduced without further delay:

- The practicing psychiatrist, in collaboration with family members (and other carers), social workers and persons who have experienced mental illness, should define: a) what are the basic needs of a person who has experienced mental illness and is about to be discharged from a treatment facility, and b) what is the minimum of resources that a family or other carer should have if the person who is experiencing a mental illness or its aftermath should be given care at home.
- The family or other carer should be given financial and other support (for example, regular home visits by a nurse) which is necessary to make the continuing treatment and care at home possible and successful.
- Social workers or nurse-visitors should be given the responsibility for a certain number of families (how many will depend on geography and possibility of transport) whom they should regularly visit. During their visit to these families, they should offer help in tasks which may surpass the capacities of the carers, as well as monitor and support the person with mental illness.
- The staff of teams which will provide outpatient care to persons who have experienced or experience mental illness should be given training focussed on work with mentally unwell people at their home. This training should be provided by psychiatrists and by carers and people who experienced mental illness.
- The facility which coordinates mental health care should establish links with other social services in the area which it will cover, and staff from these services should be invited to participate in the training of the field workers.
- The peers willing to help people who are experiencing a mental disorder or did so in the past should be offered training in matters relevant to their provision of support to people in distress. They should also be offered financial reward for their work.
- Psychiatrists who will participate in the mental health care network should, in addition to their training in clinical psychiatry, also spend a defined period of time working in the facility which organizes care for a geographical area and in the services established outside that facility. This should allow them to decide whether they would be willing to work in this type of services.
- The team managing services in a geographically defined area should carefully monitor signs of staff burn-out and foresee

measures which can be taken to reduce it.

- It is possible that some of the persons who were discharged from a facility providing mental health care will experience another episode of illness. The management of this new bout of illness should be done in the same facility which provided care in the first instance, taking into account advance directives which all persons who had treatment in the facility will have to produce on discharge.
- It is expected that the treatment in the facility and subsequently will abide by the rules ensuring the protection of human rights of the individual in treatment and of his/her carers.

The suggestions made here may require a significant reorganization of services, and an investment into the training of personnel who will provide care, of persons experiencing mental illness, and of their carers. It is also clear that it is necessary to provide ser-

vices with financial resources which are at present lacking in most parts of the world. This may be seen as or declared as impossible at present – if such is the case, it will be necessary to realize that it is extremely unlikely that fiddling with arrangements without the provision of additional resources will produce solution to the current crisis of community care for people with mental illness, their families and other carers.

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Family psychoeducation in the early stages of mood and psychotic disorders

When combined with pharmacotherapy, family psychoeducation and skills training are key strategies for preventing, delaying or minimizing the severity of illness episodes in major psychiatric disorders¹⁻³. High levels of expressed emotion – as indicated by critical comments, hostility and/or emotional overinvolvement from caregivers – are associated with high rates of recurrence in patients with schizophrenia, bipolar disorder and major depressive disorder. These familial attitudes can become more negative and fixed as the disorders progress⁴.

Early on in the illness trajectory, there is a window of opportunity for prevention or mitigation of disability in young persons. During this interval, patients and parents are usually most open to the collaborative approach of psychoeducation, in which they examine their thinking and behavior in relation to one another. Family psychoeducational interventions, however, have never completely “made it out of the shop”. Few practitioners have been trained in these methods. When psychoeducation is offered at all, it is usually in the form of unstructured support groups or canned didactic lectures. Moreover, support groups have limited reach: in a 2017 survey of 2,395 patient and caregiver respondents from the Depressive and Bipolar Support Alliance, a US-based support organization, 87% of persons with bipolar disorder were taking medications but only 10% attended support groups⁵.

When adolescents or young adults first experience symptoms of mood or psychotic disorders, both they and their families are understandably confused as to what is happening. Parents have basic questions about the diagnosis, the likely course of symptoms over time, and what treatments are likely to be successful. Unfortunately, many clinicians simply provide didactic information in rote fashion, instead of assisting the family and the patient in negotiating the complex challenges of a new illness.

What psychoeducational strategies help engage families and

patients at these stages of illness development? Consider an 18-year old male, Zak, who has had an acute manic episode requiring hospitalization. Zak’s father is able to describe the prodromal symptoms prior to his admission (e.g., rapid speech, irritable mood), but believes that his son has schizophrenia. His mother thinks that he is depressed. Zak thinks that there is nothing wrong with him. A psychoeducational family clinician will start with the provision of factual material: the key symptoms of mania and how they are different from those of a psychotic episode or normal teenage behavior. The clinician will personalize this information by encouraging Zak to describe the development of his symptoms and parents to chime in with their observations. The patient is identified as the “expert in the illness”, because “you can educate us as to what you’ve gone through and what might help you recover”. When their position in the family is elevated in this way, young people are more able to cope with the well-intended but often intrusive or critical comments of their relatives.

Moving a step further, the clinician will encourage the parents and offspring to explore the practical application of Zak’s diagnosis: what might be the early warning signs of new manic or depressive episodes? A paper or online mood chart⁶, completed daily by Zak and his parents, will help the family to become familiar with his patterns of mood shifts. The parents’ attributions about the causes of these fluctuations (e.g., “He has a biologically-based mood disorder” versus “He’s lazy”) will be addressed. The clinician will gently challenge parents as to the usefulness of certain beliefs, especially those that lead them to become harsher or expect an unrealistically high level of functioning in their offspring.

In a similar vein, families need help locating and evaluating the advantages and disadvantages of treatment options. They may be confused about how to decide on the intensity (e.g., weekly individual therapy vs. partial hospitalization) or type of care (e.g.,