CONCEPTUAL BASES OF PSYCHIATRY FOR THE PERSON

Service User and Family Perspectives on Psychiatry for the Person

Jan Wallcraft Phd[a], Sigrid Steffen[b], Michaela Amering MD[c]

[a] Honorary Fellow, School of Social Policy, University of Birmingham, UK
[b] President, European Federation of Associations of Families of People with Mental Illness, Salzburg, Austria
[c] Professor of Psychiatry, University of Vienna, Vienna, Austria

Correspondence address
Dr. Jan Wallcraft, School of Social Policy, University of Birmingham, 9th Floor, Muirhead Tower, Birmingham B15 2TT UK. E-mail: janet.wallcraft@yahoo.co.uk

Users Experience

History shows there has been no shared view about the purpose of psychiatry between psychiatrists, patients and their relatives. In previous centuries, disagreement by patients was seen as proof of unreason. Now that in most countries patients live mainly in the community, this assumption is not tenable. Current and former patients often lobby and carry out research, some with the help of non-governmental organizations (NGOs). They legitimately claim their own perspectives on care and treatment. Many argue that much of existing psychiatric research is invalid as patients were excluded from its creation.

In the UK, research carried out by academics and NGOs with input from service users demonstrates that acute hospital care is often anti-therapeutic and damaging [1,2]. Many patients have written about disrespectful treatment when they were in crisis or psychosis [3,4] and researchers have supported their views that standard treatment and diagnosis on first admission can be unhelpful, even making things worse and leading to long-term patienthood [5-8]. Studies report that patients do not feel listened to by staff [9]. On the other side of the coin, where staff do listen, this is valued [9,10].

Professional attitudes to mental illness, diagnostic systems and confinement laws are slow to respond. A diagnosis of mental illness still incurs loss of social status and employability, which discourages seeking help. Critics conclude that diagnostic labels can be counterproductive [11] or unreliable [12]. Some show that a high proportion of patients have undiagnosed trauma or abuse [13]. Others argue that mental health crises are often related to spirituality issues, yet this is overlooked within biomedical discourse of psychopathology [14].

A new trend involving personal/collective self-advocacy can be identified in the work of service users [15,16], arguing that life experience is under-rated in biomedical discourse and that real understanding of mental health problems must be based on listening to the views and life histories of patients. Some service users are setting up peer services such as drop-ins and crisis support. Self-advocacy discourse is a profound historic challenge to models based on professional expertise and power. Person-centred psychiatry must take on this conceptual challenge.

Families Experience

From the perspective of families and carers, personal experience is of paramount importance. Carers argue for their right to be partners in mental healthcare with expertise based on seeing the development, impact, and daily fluctuations of illness. Families play a vital role in care provision and often spend much more time with service users than professionals do. The involvement of carers can have a major effect on the quality of life of persons with severe mental illness [17,18] and reduces risk of relapse [19] by as much as 50% [20].

Service providers often fail to recognise the stress on carers resulting from their caring role, though the Royal College of Psychiatrists [21], do recognise the role of families. In the words of its former president, Dr. Mike Shooter: "Good practice is built on partnerships – not only between doctor and patient, but between patient and carer and between carer and doctor"

Families may help in many ways, including listening well, providing space to let off steam, and facilitating physical wellbeing. They know what the person is like when well. They can help professionals draw up emergency plans and support them in encouraging co-operation with treatment. Families may be the person's only social contact, and can often spot warning signs of a crisis. They may also help the person access services.

Carers have the right to be involved in healthcare planning and provision. The concerns of families and carers should be taken into account in updating mental health legislation, to ensure workable laws.

There are many common issues between carers, service users and professionals, including the wish for good services, support, information, advice, training and advocacy. It is in the interests of all to reduce stigma and discrimination.

Confidentiality issues have been used to deny carers information, but as the UK Department of Health argues, there are ways to ensure carers are not excluded:

Issues around confidentiality should not be used as a reason for not listening to carers, nor for not discussing fully with service users the need for carers to receive information so that they can continue to support them. Carers should be given sufficient information, in a way they can readily understand, to help them provide care efficiently.

The European Federation of Associations of Families of People with Mental illness (EUFAMI) works with policy makers and professionals and provides a lifeline for many families. Family involvement does not contradict patients' rights. Working together patients and families may be able to obtain the best possible outcomes.

The role of the Trialogue

The "trialogue" model [22] of 3-way discussions between service users, family members and professionals has been used in a number of countries to break down barriers and address specific issues for service-users and relatives.

It promotes communication beyond role stereotypes. Active involvement of patients, service users, carers, relatives and friends in mental health care and research helps develop integrative community mental health work. Co-operation is needed also to solve methodological problems of evaluative research and generate new models of needs-orientated interventions. Changes in structures as well as forms of communication are needed for patients and providers to accept each other, respectively, as 'experts by experience' and 'experts by training'.

In Trialogue-groups service users, carers and mental health workers meet regularly in open forums, outside therapeutic, familial or institutional contexts, to discuss the experiences and consequences of mental health problems and ways to deal with them. This setting makes it possible to share knowledge and insight. It functions as a starting point for trialogic activities at different levels and topics. Trialogues are inexpensive and a many of its participants seem to find them beneficial. Current ideas for the scientific evaluation of Trialogues pose conceptual and methodological challenges.

Psychiatric organisations should support Trialogues as well as available advocacy and self help groups so that all together can create extended conceptual bases for psychiatry in the 21st century.

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