Recovery: is consensus possible?

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I did not feel comfortable reading Bellack and Drapalski's paper. Perhaps this is because my journey to this point has been different from theirs. Mine started with lived experience of major mental distress and mental health services in my late teens and twenties. Since then I have applied the values of the international consumer/survivor movement to urge services and wider society to respect the madness experience, facilitate pathways through it and treat us as equal citizens. In a word, these values sit on a platform of self-determination. As a mental health commissioner in New Zealand, I had a responsibility to help articulate what a recovery approach means in the national context. This included a critique of medical and other deficits approaches, a questioning of compulsory treatment and promoting social justice as a key to recovery; these themes are not always strong in the international recovery literature (1).

The core of my discomfort probably arises from the fact that I do not sit on the same side as the authors in the "broad church" of people who sign up to recovery. Bellack and Drapalsky seem to be in the aisle which lacks a deep critique of the dominant beliefs and structures that drive service and societal responses to

madness. For some of us who were educated primarily through our lived experience and the analysis of the consumer/survivor movement, a critique of these beliefs and structures is essential for the transformation of services and societies so that they support recovery.

Bellack and Drapalski describe recovery as a model, but I have always seen it more as a philosophy. A model is a template, process or design that guides what people do, whereas a philosophy in this context is a set of beliefs that guides the moral value we ascribe to what people do. A model can be empirically tested, but a philosophy can only be argued because of its fundamental nature. I believe we should determine the moral value of a model of practice before we apply empirical research to test its efficacy. This put me at odds with Bellack and Drapalski's lament that because the "recovery model" is based on personal accounts, qualitative studies and political consensus statements, it is vague and hard to test. This may be frustrating for some research psychologists who seem to rate empiricism over values, but it does not worry me.

I also felt the authors were slightly critical of consumer/survivor leaders and academics for failing to come up with a tidier ensemble of data for them to analyse and test. If this is the case, I believe their criticism is ill-founded. Although there are a growing number of

consumer/survivor academics (and who knows – the authors may count themselves among them), they are a tiny, scattered and poorly resourced group. To my knowledge, there are no departments of user/survivor studies anywhere in the world, but of course there are hundreds of well-resourced psychology departments.

I am not against aggregating people's

experiences or measuring indicators of recovery in individuals or populations, but I get the impression that the authors' primary loyalty is to the application of a rather reductionist form of science, whereas mine is to the honouring of lived experience and to justice in service systems and in wider society. This is why the authors and people with a world-view close to mine might have difficulty

reaching a consensus on how to apply research to recovery, but it is important that we try.

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tive experience”, rather than simply relying on clinicians’ definition of a “good outcome”. Bellack and Drapalski describe how the iterative development of their MARS scale was led by six clinical scientists, who supplemented their work through interviews with six independent experts and a panel of consumers. While consultation with consumers is a welcome advance on *no* consultation with consumers, such a model retains the familiar balance of power, whereby consumers’ knowledge regarding recovery is positioned as far less “expert” than that of the clinical scientists and “independent experts”. Contrast this with the consumer-led model to develop outcome measures described by Rose et al (8), which has been used successfully to develop outcome measures for cognitive-behavioral therapy in psychosis (9) and in assessments of continuity of care (10). This model develops outcome measures entirely from the perspective of mental health service users, and is premised on the argument that “it is mental health service users who know from the inside what treatments and services benefit them and which are detrimental” (8).

Bellack and Drapalski would no doubt disagree that the development of outcome measures for recovery ought to follow such a route, given their argument that these measures must also be “viewed as relevant by scientists, clinicians, family members and legislators”. And this leads us to the nub of the issue. Bellack and Drapalski wish to move the recovery model away from “political decisions” (which characterize the consumer movement) and towards “empirical evidence of the validity of the model” (which characterizes the practice of science). Rose’s alternative method for developing outcome measures demonstrates that this is a false divide: *all* empirical evidence regarding the validity of the recovery model will be inflected by “political decisions” regarding whose perspectives count in adjudicating a good outcome.

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Consumer perceptions of recovery: an Indian perspective

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In many developing countries, including India, the consumer/family movement is still nascent, albeit growing in strength gradually. It is also likely that some of the rather paternalistic treatment settings do not value or seek the opinion of consumers as often as they should be doing. In this context, we undertook at the Schizophrenia Research Foundation (SCARF) a small exploratory study to ascertain consumer perspectives of recovery from schizophrenia.

SCARF is a non-governmental not-for-profit organization which runs outpatient services in urban Chennai, India as well as in rural and semi-urban areas. A brief study on the patients’ perspectives on the indicators of recovery was conducted in SCARF outpatient department in Chennai among patients with schizophrenia and schizoaffective disorder. An inclusion criterion was the presence of at least partial insight (i.e., the patient acknowledged having a mental disorder).

Of the 164 patients who fulfilled the entry criteria and who were approached

during a period of 30 working days, 100 gave consent to participate in the study. They were asked open ended questions regarding what they personally considered as indicators of recovery. Then, we submitted them a list of possible indicators of recovery generated on the basis of available literature, consultation with other mental health professionals and prior discussion with 25 patients and their families. Snowballing technique was also used whereby new items generated during the interviews were added to the list for the next interview. The patients were then asked if their recovery had to be “externally validated” by some source such as their family, employer, treating team, or if it was “internal”, whereby they only needed to be convinced that they had recovered.

From the interviews, a total of 31 indicators were generated. The most common theme that emerged was the equation of recovery with the absence of symptoms (88% of the respondents) and not having any more relapses (73%). Getting back to their regular lives in terms of functioning (70%) and being able to handle the associated responsibilities (62%) were also deemed important. To 65%, recovery

ery meant not having to take medicines any more. More women (80%) than men responded this way.

Among the respondents, all the students, 71% of the unemployed, 66% of those attending a sheltered workshop at SCARF and 63% of those employed mentioned "holding on to a job" as the most important indicator of recovery. About 35% mentioned getting married and having children as indicators.

Previous work from this centre has underscored the importance of work and occupation in the recovery of patients (1,2). The fact that health insurance in India does not cover mental illness and the state does little in terms of welfare programmes for this group of people makes it critical for many of these patients, specially those from lower economic groups, to find a job to support themselves and their families.

Although personal attributes such as self-efficacy did not figure in the list, they appeared to be quite central to many of the themes which emerged (e.g., statements about efficacy in social and work situations, the need to get on with life, to become independent and to take decisions on one's own).

Patients mentioned internal validation six times more frequently than external validation. In particular, many patients stated that their perception that they were good on the job was more important than the employer's perception.

A heartening feature was that, although the group consisted of primarily chronic patients with a mean duration of illness of about 11 years, none thought that recovery was impossible to achieve and all were able to articulate personalized indicators of recovery.

It is unclear from this study whether our patients viewed mental health service as too paternalistic and felt overwhelmed by a sense of hopelessness and helplessness, as described by Belack and Drapalski. This needs further research, possibly in varied health care settings. It appears that this sample of patients had a fairly realistic view of recovery and accorded a high premium to social functioning, specially with respect to employment.

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Consumer recovery: a call for partnership between researchers and consumers

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Consumers of mental health services, especially in Africa, will agree with Belack and Drapalski that time to develop consumer recovery models backed with empirical evidence is now. Evidence on the ground reveals that recovery models have a biomedical approach of curing the disease as a primary focus and not promoting consumers' ability to stand the challenges of living with a mental health condition.

As a case, Zambia has two national recovery institutions that accommodate 160 consumers and were expected to receive central funding for operations. Alas, for many years now funding has not been allocated to these institutions, hence affecting service delivery (1). These centres have become a dumping ground for persons with mental health conditions, contributing negatively to the recovery process. This is unacceptable and a violation of the human rights of persons with mental health conditions. It is a human rights violation because it denies persons with mental health conditions an opportunity to attain and maintain maximum independence, vocational ability and full inclusion and participation in the community and in all aspects of life (2).

Recovery services must be available to persons with mental health conditions as close as possible to their own communities, including in rural areas (3). Comprehensive recovery programmes and services should be organized, strengthened and extended, based on the multidisciplinary assessment of individual

needs and strengths. It is our hope that we develop recovery models that will allow persons with mental health conditions to realize their own abilities, work productively and fruitfully and be able to contribute to their own communities (4). This includes communities who seek to provide an environment that enables persons with mental health conditions to maximize their own potential, to improve their quality of life and have the same opportunities and responsibilities as people who do not have impairments. We see recovery services as a vehicle to poverty reduction, information sharing and persons with mental health conditions taking responsibility for their own development.

In the development of recovery services, it is of paramount importance that persons with mental health conditions take part on an equal basis with others. It is therefore essential to promote actively an environment in which persons with mental health conditions can effectively and fully participate in the construction of recovery models without discrimination. Our personal experience stands to provide a strong and unshakeable influence to ensure that recovery models are evidence based. Our life experience stands ready to direct and guide the development of consumer-centred recovery models that are comprehensive.

To achieve this is a call for partnership between researchers and consumers. This call for partnership in recovery is crucial, despite not receiving the attention it deserves. Opportunities for promoting evidence based recovery models are available through the growth of networking among people active in the field

of mental health. These networks should be formed by professionals, family members and persons with mental health conditions.

Partnership is the way to go. The importance of partnership in developing evidence based recovery models is that it brings the combination of complementary skills and wider pool of knowledge. It is also cost-effective as each partner will specialize in a certain aspect of the recovery model during development. It further goes to provide the moral support that

allows for more creative brainstorming.

Therefore, there is need for researchers and consumers to invest in developing partnership, so that evidence based recovery models are constructed globe over, for the benefit of the consumers, more especially those living in low and middle income countries, because they are worst hit in terms of lacking recovery services.

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