Trans-Cultural Study of Recovery from Severe Enduring Mental Illness in Chennai, India and Perth, Western Australia

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Abstract Interest in consumer perspectives of recovery from severe enduring mental illness was kindled in the United States of America (USA) during the 1970's and gathered momentum in the decades that followed. Research based on consumer narratives resulted in a consumer model of recovery. In the absence of similar international research intensity, the consumer recovery model from the USA was carried unchecked beyond its borders with little regard for cultural differences. This raised the question: How do consumers from different cultures construe recovery? To answer this data from a study conducted in Tamil Nadu, India were compared to data from an independent study conducted in Perth, Western Australia. Results showed remarkably similar views between consumer perspectives of recovery. Both samples revealed a strong clinical orientation toward recovery followed by social role functioning and to a lesser extent a personal orientation toward recovery. However, participant explanations for these differed, which clearly related to cultural values. We concluded that rather than polarizing the concepts of recovery related to a severe enduring mental illness it would seem more productive to consider the different concepts of recovery as the pillars of a unified framework that is culturally sensitive.

Keywords Transcultural · Consumers · Recovery · Schizophrenia · Enduring mental illness

Introduction

The discussion of the meaning of recovery from an enduring mental illness continues to be a dominant issue in the psychiatric literature. Allegorically it can be compared both with the story of the blind men and the elephant and Alice's experience in wonderland. In the first instance, blind men grasped different parts of an elephant. The elephant took on a different meaning for each of the men depending on the direction from which it was approached. In Lewis Carroll's tale of Alice in Wonderland, Alice met Humpty Dumpty. The two characters had a discussion about the meaning of words; Humpty explained that when he used a word it meant just what he wished it to mean. Alice questioned whether you can make words mean different things [5]. As Bellack observed "...recovery can be defined so broadly as to make its achievement unimportant" [4].

The concept of recovery from a severe mental illness has a long history. Initially from a medical perspective it was viewed in a clinical context involving the remission of symptoms. Early in the twentieth century Manfred Bleuler drew a distinction between clinical recovery and social recovery in persons who had been diagnosed with schizophrenia, the former consisted of medical criteria and the latter social-role-functioning [20]. Based on this distinction, Bleuler developed a recovery scale which included four determinants: "employed, resumed former role functioning, not seen as mentally ill by the family and no overt psychotic symptoms" [4].

During the second half of the twentieth century a third view of recovery emerged from the consumer movement, namely personal recovery. This concept of recovery focused on factors that facilitated recovery, for example: hope, optimism and empowerment. During the 1980's this concept

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of recovery progressed steadily up the psychiatric agenda resulting it being called the “decade of recovery” [2].

Anthony’s oft cited definition of recovery, involving the development of new meaning and purpose in one’s life as one grew beyond the catastrophic effects of mental illness, has influenced policy and practice across high income countries, including Australia. Australia’s National Mental Health Policy states:

Recovery is a personal process of changing one’s attitudes, values, feelings, goals, skills and/or roles. It involves the development of new meaning and purpose and a satisfying, hopeful and contributing life as the person grows beyond the effects of psychiatric disability [3]

Liberman developed a more inclusive definition of recovery from the effects of a mental illness by incorporating: clinical, psychosocial and a personal perspective in which, symptoms and cognitive dysfunctions are in abeyance, the person actively participates in community life; they value hope for the future and satisfaction in their everyday lives, have a sense of empowerment, self-respect and personal responsibility [9].

In Western high income countries personal recovery has dominated discussion at a number of levels including research and policy development. However, this construction of recovery has emanated largely from the United States of America (USA). A study of recovery by Andresen et al. is often cited as an Australian study representing the views of Australian consumers. However, this study, conducted by an Australian researcher, was a meta-analysis of the literature of USA consumer narratives [1, 14, 15].

Tooth et al., who conducted the earliest study of Australian consumers’ perspective of recovery from schizophrenia, reported that it was not possible to form one definition of recovery, however, they identified a number of markers of recovery including: “taking responsibility, being like normal people, peace and contentment and being symptom free” [18]. A later grounded theory study of consumer perceptions of recovery from a severe persistent mental illness conducted in Western Australian (WA) found that consumers in WA construed recovery in both clinical and psychosocial terms, which could be complete or partial [8]. The results differed from the published research emanating from the USA. Henderson’s findings had much in common with those of Tooth, in particular peace and contentment and being symptom free.

While not yet embedded in the mental health policies of non-western countries, the philosophy and principles of personal recovery have begun to find their way into some low income countries with little consideration for socio-cultural diversity. Tse et al. described the Hong Kong mental health system as being clinical-centric and argued

that this needed to change to a personal recovery orientation. They did not, however, elaborate on how this might occur in a culturally sensitive way [19]. In contrast, Ng et al.’s study of people diagnosed with schizophrenia in Hong Kong identified differences in functional recovery where independent living was seen as being different in Hong Kong than in some Western countries [11]. These researchers observed that “Most young people live with family members until they marry and some even after they are married”.

Interestingly consumer views that coincide with a clinical view of recovery seemed to be discounted. Slade et al. for example, in undertaking the validation of a consumer framework of recovery excluded any studies that had a sense of clinical recovery or even “getting back” [14, 15]. In so doing, studies from low income countries were not included even though the authors concluded that research was required within other cultures. This contrasts with Wunderink et al. who commented that the clinical concept of recovery did not necessarily exclude a consumer perspective of recovery—Stanhope and Henderson supported this [8, 16, 21].

Noordsy et al., clearly identified that personal recovery defined in the literature applied to the culture in which it was generated—the USA and that values associated with personal recovery have influenced both policy and practice [12].

Greenberg et al., caution that, in relation to service provision, an individualistic material culture has “implicit values that may be neither appropriate to all cultures nor suited to all individuals” [6]. This is not only relevant in relation to low income countries but also high income countries.

This raised the broad question: How do consumers from different cultures construe recovery?

The two writers, who met at the International Conference on Schizophrenia—IConS V in Chennai, had independently conducted research into consumer perceptions of recovery in their own countries—India and Australia, and recognised the potential to collaborate and explore similarities and differences in recovery perceptions of consumers in a low income country (India) with those in a high income country (WA). Rather than review the literature for cultural differences and similarities of recovery we recognized the potential to conduct a comparative analysis of the original data from the Schizophrenia Research Foundation (SCARF) study “Recovery – What the Patients and Families Want” with the original data from the grounded theory study; “Western Australian consumers’ perceptions of recovery from a severe enduring mental illness”. This paper reports the findings of this collaborative research and discusses the implications for a cultural understanding of recovery from psychosis.

The study received approval from both the SCARF ethics committee and the University of Western Australia Human Research Ethics Committee. Participants in both studies had given written informed consent for the original studies, and as no new data were to be collected, both the SCARF and UWA ethics committees accepted this consent as valid for this study.

Methods

The study reported here involved the comparative analysis of the findings of a study conducted by SCARF in Chennai, Tamil Nadu with the findings of a study conducted in Perth Western Australia. The original SCARF study comprised 100 participants with a diagnosis of schizophrenia, and who did not have a co morbid psychiatric or neurologic disorder, history of substance or alcohol abuse. Participants were asked open ended questions regarding what they personally considered as indicators of recovery. Then, a list of possible indicators of recovery generated from the available literature, consultation with other mental health professionals and prior discussion held with 25 patients and their families was shown to them. The snowballing technique was also used, whereby new items generated during the interviews were added to the list for the next interview. This study revealed 21 indicators of recovery.

The original Perth study used a grounded theory method employing unstructured interviews to elicit what recovery meant to 15 people who lived in an outer metropolitan suburb, attended a mental health outpatient clinic and had a diagnosis of a schizophreniform or bi-polar disorder. The inclusion criteria included: persons who could converse well in English, give a coherent account of their experiences and aged 21–55 years of age. Although not a requirement of the study, the participants were born in either, Australia of English extraction, born in England, or born in Europe. For full details of this see Henderson [8]. As with the SCARF study persons who had a co morbid psychiatric or neurologic disorder, were excluded. This study identified a core category Getting Back, which referred to getting back what had been lost and which comprised seven components.

To make the data between the Perth and SCARF studies comparable mental health professionals at SCARF were asked to group the 21 indicators of recovery into categories. Indicators like absence of symptoms, stopping medication, no worsening of symptoms were grouped under the category Symptom Free. Similarly getting back to work, taking care of the family, participating in family functions, sustaining a job were categorized under regaining social role functioning. This resulted in a total of seven categories. When compared with the Perth sample a total nine categories emerged, which included: being free of symptoms, social role functioning,

Table 1 Participants characteristics are summarised in the following table

VARIABLES	SCARF (n = 19)	WA (n = 15)
Gender	Male—10 Female—9	Male—8 Female—7
Mean age (years)	37.6 ± 7.2	44 ± 8.1
Education	15.1 ± 7.2	13.5 ± 8.1
Diagnosis	SZ—17, SA—2	SZ—5, SA—1 BPD—7, Dep—2
Age at onset (years)	25.16 ± 7.0	24.2 ± 8.1
Duration of Illness (months)	150.9 ± 7.2	208 ± 8.1
Living arrangements	Live alone = 0	Live alone = 9

regaining cognitive functioning, social inclusion, self-esteem, empowerment, having a healthy life, peace of mind and thinking positively about mental health.

The next step to facilitate comparability involved the first author selecting a subset of 19 persons from the 100 participants in the original SCARF study who gave their responses in English and whose characteristics were similar to the Perth participants. We matched the two samples based on: gender, age, level of education, diagnosis, age of onset, duration of illness, and living situation. The samples were not matched for employment due to the considerable differences between India and Perth in relation to government benefits provided to support persons with a psychiatric disability. In Australia for example, people had access to a disability pension, employment support agencies, as well as supported employment opportunities. In comparison there was a lacuna of government support in India (Table 1).

Among the participants, gender distribution was equal, in relation to age SCARF subjects were slightly younger compared to the Perth participants. The SCARF study focused only on schizophrenia and schizo affective disorders whereas the Perth participants were a mixed group comprising people diagnosed with schizophrenia or an affective psychosis. Interestingly the two groups were dissimilar in relation to their living arrangements. All SCARF participants lived with their families whereas the majority of the Perth participants lived alone—this could be attributed to cultural differences. There were marked differences in employment opportunities, access to government support and also relationships between the two groups and so they were not matched on these variables.

Findings

In the final analysis, nine categories emerged from the data. These included: being symptom free, social role functioning, social inclusion, regaining cognitive functioning,

empowerment, healthy life, self-esteem, having peace of mind and positive thinking. The strongest indicators of recovery among the participants of both groups were being symptom free (98 %) and regaining social role functioning (82 %). There was agreement between the two groups on being symptom free, social role functioning, social inclusion and regaining cognitive process. The most common category that emerged for the SCARF participants was the absence of symptoms (88 %) associated with absence of relapses (73 %), and no longer having to take medicines (65 %) the latter was particularly so for women. Getting back to regular lives in terms of social functioning (70 %) and being able to cope the associated responsibilities (62 %). Self-esteem, having peace of mind and thinking positively about mental health were unique to the Perth participants, while empowerment and a healthy life were unique to the SCARF participants (Fig. 1).

Although a number of indicators for recovery between the two groups matched, the reasons behind recovery differed, for example; participants in Perth associated symptoms and medication with illness—being symptom and medication free meant they no longer had an illness. However, controlling symptoms for the SCARF participants was important to maintain harmony in the household. And so while the properties of recovery, identified in the categories, described by the participants in the SCARF study and those in the Perth study matched, we found that there were differences in the explanation of recovery which were accounted for by cultural differences.

Being symptom free had a major impact on the other indicators of recovery, particularly social role functioning and social inclusion, which were also inter-related. As mentioned we did not match the samples for employment, however, it was a property of the category social role functioning. Within the SCARF participants this was related to the division of labour, whereby women were involved in domestic duties and men provided the income. The division of labour was less noticeable in the Perth participants, where women were more independent. Among SCARF respondents, 100 % of the students, 71 % of the unemployed, 66 % of those attending a sheltered workshop and even 63 % of those employed mentioned “holding on to a job” as an important indicator of recovery. In addition, 35 % mentioned getting married and having children as indicators. Marriage was not mentioned by the Perth sample, and raising children was only mentioned by those who were parents.

With regards to social inclusion this was more strongly related to participants with a shorter duration of illness (DOI). SCARF participants talked about social inclusion as their indicator of recovery because they were being constantly discriminated against or rejected in their community. They also had the need to hide their mental illness

Fig. 1 The similarities and differences between the SCARF and Perth samples are summarized below

from the people around them. Faced with rejection at work, among relatives and at social gatherings, individuals concealed the presence of mental illness and started withdrawing from social events. This was also consistent with the findings of the Perth participants who used concealing as a means of avoiding being stigmatised. For example, a participant who had regular psychiatric out-patient appointments during work time told her co-workers that she attended a medical clinic not a psychiatric clinic. And a clinical psychologist who said if other professionals knew that she had been treated for a mental illness she would not get any referrals. Patients receiving treatment at SCARF, reported being unable to get a job if mental illness was disclosed. Even the professionals at the job training centre of the same facility felt that it was very difficult to place patients in outside employment. These were the major reasons why patients stopped seeking work altogether.

Although we did not match the samples for employment, work was a socially integrating force and contributed to a sense of social inclusion. To be excluded from the workforce created material deprivation, eroded self confidence, created a sense of isolation and marginalization. Hence finding a job and retaining was identified as a property of social inclusion and contributed to recovery. This also contributed to the perception of being accepted as a normal person in society.

Interestingly, we found that female participants in both groups rated cognitive functioning more highly than male participants. Of the 16 females, 13 (81 %) identified regaining cognitive functioning as an important indicator, whereas only 7 of the 18 males (38 %) identified cognition as an indicator of recovery. Regaining cognitive functioning was identified as important by both employed females and housewives, because impairment hindered their day-to-day routines. In the two groups the majority of the males did not contemplate becoming employed and so their focus

was not on improved or regaining previous cognitive levels. These then were the main similarities.

Two main differences emerged between the SCARF participants and the Perth participants; the first related to empowerment and the second to having a healthy life style. Being empowered and having a healthy lifestyle were not reported by the Perth participants as indicators of recovery, rather they viewed self-esteem associated with self-confidence, having peace of mind and thinking positively as indicators.

Empowerment emerged as a category particularly from the female participants attending SCARF and included “Being Independent, Travelling alone, Managing Finances”, unlike in Perth where empowerment was reported to be associated more with decision making around treatment. Empowerment as a category varied from the Perth perspective because the SCARF participants always had a family member for support or they relied upon their treating consultants to take all decisions regarding treatment. In Indian culture patients and families have given a “Godly” status to the medical doctors. Thus in India, patients leave the decision making regarding treatment to their doctor. However in high income countries, such as Australia, independence is encouraged including ones health. Hence consumers in the mental health sector tend not to blindly accept the decisions of doctors. Henderson [8] reported an instance of a consumer entering into a discussion with his psychiatrist about the dose of his medication; this resulted in the psychiatrist prescribing a lower dose.

There were many similarities in this study between the SCARF and Perth participants. The differences mainly related to emphasis. Of significance were the underlying reasons for the views of recovery, which we identified as being culturally determined.

Discussion

We report the findings of this collaborative research and discuss the implications for a trans-cultural understanding of recovery from a severe enduring mental illness. Overall, the findings of our study run counter to the dominant view of recovery emanating from the USA which construes recovery in a more existential way. Of note is the language used in the USA psychosocial rehabilitation literature; namely the use of the term consumer rather than patient. Indeed the policy in these journals is that the use of medical terms relating to recovery is unacceptable. The language in this article is that of the participants at SCARF and in Perth and how they expressed their views of recovery.

There were similarities and differences between the participants attending SCARF and in Perth. The

commonest aspect was regaining what they had lost, particularly associated with an external locus of control. A study by Stanhope, which compared USA and Indian participants’, identified cultural differences of recovery where USA consumers had an internal locus of control versus the Indian participants who had an external locus of control [16].

The differences between the SCARF and Perth samples reflected the two cultures particularly in relation to independence and interdependence, and family involvement in recovery. Thara et al., observed that, in a socio-cultural context “The concept of independent living is not applicable to the Indian situation” [17]. There is no expectation of women with marital prospects to work, thus they are dependent on their families. Also, because of limited beds and concern about stigma consumers primarily live with families. Thus in order to decrease disruption within the home there is an emphasis on reducing symptoms which is related to medication adherence. However, men needed to remain sufficiently well in order to fulfil their role expectations. In other words they appreciated the need to take medication as it enabled them to maintain productive activity. In comparison, self-reliance and independence are features of the Australian culture. This is encouraged by government support provided by way of economic benefits such as a disability pension, supported housing and free or subsidised medications. Although dependent on the state, these benefits provide people with a psychiatric disability to live independently of their families.

Social inclusion particularly associate with discrimination, was similar for both the SCARF and Perth samples and they both used similar strategies to avoid being exposed. Loganathan and Murthy noted that men with schizophrenia reported hiding their illness in job applications and from others [10]. However in the Perth sample, both men and women concealed their illness from prospective employers. Although there were only 15 people in the Perth sample, the original study identified concealing as an integral part of the core variable. This was consistent with an earlier study conducted at SCARF which revealed the stigmatizing aspects of schizophrenia associated with fear of rejection by neighbours and the need to hide this from others.

Empowerment per se did not emerge as a category from participants with schizophrenia when they were asked about their perspectives on recovery. Instead they spoke about “Being Independent”, “Handling and managing money”, “Travelling alone”, “Taking decisions on their own” as important indicators of recovery. The writers considered these factors to be properties of the broad category of Empowerment. When viewing empowerment in the Indian context it is very important to consider the role of the family. Research provided evidence that the Indian

family was especially supportive of members with schizophrenia. It is the Indian tradition of interdependence and concern for near and dear ones. The families and caregivers role have been integrated in the treatment plans and policy making. In the study reported here, 40 % of the Perth participants lived with their families or friends while 100 % of the SCARF participants lived with their families. Persons with Schizophrenia in Chennai were never allowed to be independent or given an opportunity to be on their own. In spite of the burden and frustration among caregivers they continued to provide support. Hence the need to be independent became an important indicator for participants to consider themselves recovered.

Although a number of indicators for recovery between the two groups were similar the reasons behind recovery differed, for example; participants in Perth associated symptoms and medication with illness—being symptom and medication free meant they no longer had an illness. One way of overcoming this was through reframing whereby they adopted positive thinking and viewed taking medication as a means to remain healthy and reduce the risk of relapse in much the same way they took vitamin C to ward off a cold [8]. Controlling symptoms in the SCARF participants was important to maintain harmony in the household. And so, while the properties of recovery described by the participants in the SCARF study and those in the Perth study were similar, the explanation of recovery was accounted for by cultural differences.

To be meaningful, therefore, operational, culturally sensitive definitions of recovery are required. The International Pilot Study of Schizophrenia (IPPS) conducted by the World Health Organisation concluded that it was possible to use the same standardised criteria and instruments to compare the outcomes of schizophrenia across cultures [13]. In a follow-up International Study of Schizophrenia (ISoS) the Bleuler recovery scale was one of the instruments used to determine the extent of recovery of participants [7]. Bleuler's scale incorporated both clinical and psychosocial elements. However, it could be adapted to include a personal perspective of recovery; this could then be used in future research to advance knowledge of recovery in a cultural context. Clinical, psychosocial and personal perspectives have the potential to provide the pillars of a culturally sensitive recovery framework rather than perpetuating an ethnocentric polarised perspective.

Limitations

This study involved post hoc data analysis of two studies that employed differing methods, consequently the findings need to be viewed with caution. The studies were not part of an integrated mixed methods research design; rather

they were conducted independently of each other and were designed for different purposes. In the Perth study the indicators' of recovery emerged from the participants whereas the indicators of recovery in the SCARF study were generated from consumers, families, the literature and health professionals. These indicators were then categorised by health professionals independent of the study. While this approach maintained objectivity it ran the risk of forcing the data into preconceived ideas. There was no mechanism in place to reduce the risk of this happening. In addition, the Indian participants comprised a selected sub sample of a larger sample in order to match the Perth group as closely as possible for comparability and, therefore, were not necessarily representative of the substantive area in the Chennai population. This latter aspect is arguably the most important of the limitations as it may well be that the similarities in the categories identified occurred by coincidence. These limitations notwithstanding we are of the view that the findings are worthy of note; particularly the importance of attending to culture when attempting to present an overarching view of recovery.

Conclusion

It would seem axiomatic to state that any concept of recovery must be construed in a socio cultural context this, however, has largely been ignored in the literature. The prevailing perspective of recovery from a severe enduring mental illness which emerged from the Western developed countries dominates the landscape. This has influenced mental health policy and or rehabilitation services in other countries with little regard for the cultural differences that exist. As one person in Henderson's original study stated so succinctly "Recovery is the ability to fulfil my cultural mandate". Attempts to export recovery concepts from high income countries to low income countries without due consideration of the culture is fraught with problems. The consumer model of recovery reported in the literature opposes any reference to or inclusion of clinical recovery. This discounts the views of consumers for whom being symptom free and regaining what they have lost is central to how they construe recovery. More importantly it ignores recovery in a cultural context. It would seem more productive, therefore, to consider the different concepts of recovery as the pillars of a unified framework that is culturally sensitive.

Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

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