



## **Recovery focused interventions: Perceptions of mental health consumers and their case managers**

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### **Abstract**

The concept of recovery has emerged as a central tenet of the mental health consumer movement, and is increasingly informing service development and evaluation. Key factors that contribute to recovery have been identified in both consumer writings and research, but few studies have explored the extent to which mental health workers and mental health consumers share perceptions of the relative importance of those factors. In this study a new instrument was developed to measure the importance of recovery factors as rated by paired mental health consumers and case managers. A pilot administration to 15 consumers and their case managers revealed that the measure was sensitive to differences in perceptions. Differences were found in the areas of medication, strengths-based interventions and perceptions of the relationship with the case manager and service. Case managers tended to rate their level of recovery-focused activity higher than did consumers. The instrument has potential to be used in a larger study to further establish its validity and reliability.

### **Keywords**

*consumers, case management, recovery, mental health*

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### **Introduction**

Until recently, the outlook for most people experiencing severe mental illness was confined to a scenario that depicted an incurable, life-long condition, where daily adherence to medications over a lifetime offered only a slight hope of regaining something resembling a productive life. Other 'givens' within this scenario appeared to be take no risks, remain dependent on others, and lower any expectations of anything more than a marginal existence (Deegan, 1996, Schmook, 1994).

In recent years, a 'recovery vision' has arisen in mental health services, a shift in attitude that has been influenced by two major sources. The first of these is the growth in the consumer movement that has strongly advocated for change and recognition of consumer rights. The second is the growing body of knowledge in both the clinical and rehabilitation areas that has redefined to some extent the way in which the long-term prognoses of consumers are defined (Anthony, 2000).

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### ***Definitions of recovery***

Several operational definitions of recovery exist, and more recently, the concept of recovery from mental illness has emerged as a central tenet of the consumer movement. Recovery has been recognised as a possible clinical outcome in traditional psychiatric epidemiology, defined by Watkins (1996) as *clinical recovery* (or remission), and usually focused on the absence of symptoms. Clinical recovery has also been referred to as syndromal recovery, referring to the absence of specific DSM-IV episode criteria (Tohen et al., 2000). *Social recovery*, on the other hand, implies that although the person has not been 'cured' of their 'illness', they have been able to achieve financial and domestic independence (Watkins, 1996). Clinical and social recovery are the most familiar definitions of recovery.

The term has assumed a more specific meaning within the consumer movement. It is not simply a matter of remission of symptoms or restoration of social functioning, and may take place in the absence of either of these outcomes. Recovery has been described as a journey (Deegan, 1996; Gagne, 1996), and consumers have drawn the distinction between the *functional* (or rehabilitation) view of recovery, and an *empowerment* view of recovery (Fisher, 1997). The functional view places recovery from mental illness on the same footing as recovery from severe physical disability such as paraplegia, where recovery may occur even though the major injury is still present, and is defined as "a unique process of changing one's attitudes, feelings, goals, skills and/or roles" (Anthony, 1993).

According to the empowerment vision, full recovery is possible for everyone; treatment is part of self-managed care, which combined with social supports, helps the person who has been labelled as 'mentally ill' regain membership in society and regain the sense of being a whole person (Fisher, 1997). Critical to the empowerment view of recovery is the notion that the person is not only recovering from the distress of illness, but from the effects of stigma and discrimination in a 'disabling culture' (Moore, 1996). However, there is no one

conceptual framework that can be described as a 'consumer definition' of recovery; as illustrated below, consumers have ascribed their recovery process to numerous factors, including those associated strongly with clinical recovery, such as medication compliance.

### ***Factors conducive to recovery***

Across all four definitions of recovery, factors that are conducive to consumer recovery have been identified. An overview of these factors revealed several areas of inquiry that could be incorporated into the instrument that was developed in this study. Several authors (Sullivan, 1994; Jeffs, 1997; Masching, 1996; Francell, 1996) have identified appropriate *medication use* as critical to recovery from some forms of mental illness, especially schizophrenia and bipolar disorders, albeit with often-considerable difficulty in locating adequate therapeutic effect and minimum intrusive dosage. *Knowledge and acceptance* that one has an illness, which often includes assuming a degree of personal responsibility for emotional well being, has also been identified as a key issue in recovery (Deegan, 1996). Between 14 and 43% of participating consumers have identified *spirituality* as assisting their progress towards recovery (Hogan & Roth, 1999; Sullivan, 1994), either as a primary resource for hope (Fallot, 1998) or as a sustaining force in maintaining a sense of coherence and purpose in life (Sullivan, 1998).

*Collaborative treatment planning* has been identified in both the empowerment and the rehabilitation visions of recovery as fundamental to the re-assignment of power structures inherent in the worker-dominated 'expert' model to one of partnership and mutuality (Fisher, 1994; Williams & Collins, 1999; Hogan & Roth, 1999). Early studies on recovery have noted the role of *self-will and self-monitoring of symptoms* (Sullivan, 1994), with later documentation by consumers describing the turning-points of recovery occurring when they began to assume more active roles in taking responsibility for their illness, treatment and progress (Schmook, 1994; Frese, 1993; Champ, 1998; Koehler, 1994).

*Strengths-based interventions* have been shown to assist consumers to reach more of their goals (Rapp & Wintersteen, 1989), supporting the proposition that major inhibitors of recovery include low expectations and disempowering practices (Deegan, 1997). Additionally, the *role of people who stand by the recovering consumer* (Anthony, 1993) has been identified as a major recovery factor, reflecting the findings of Davidson and McGlashan (1997) that 'social deprivation' made a more substantial contribution to re-admission to hospital than symptomology or level of functioning.

### ***Gaps between principles and practice***

Many of the principles enunciated above have become enshrined within policy and planning statements designed to guide public mental health practice in Australia (National Mental Health Strategy, 1996). Mental health professionals are expected to work with consumers in a collaborative manner, within a broad recovery framework. However, while these principles are widely accepted, there has been limited research so far that has investigated whether or not the actual practice of mental health workers reflects these ideals.

Such research as has been published suggests that there may be significant gaps between principle and practice, or at least between the perceptions of consumers and practitioners as to what practices are actually occurring. Campbell (1996) observed that consumer-focused research reveals wide discrepancies between consumers and professionals on the relative importance of treatment goals, identification of problems, and needs and preferences for support. Similarly, comparative studies by Brown et al. (1997) and Lang et al. (1999) have noted conflicting perceptions between the two groups, which may compromise interventions and have implications for treatment planning. A recent study by the Mental Health Council of Australia (2000) indicates that, anecdotally, National Standards specifying participation by consumers in treatment planning (Standards 11.4 and 11.4.11) have not been implemented; treatment is not developed collaboratively and there is a lack of information regarding medication choice and side-effects.

### ***Aims of the study***

Given the limited empirical research into recovery focused mental health practice, this study aimed to develop a method of identifying and quantifying the perceptions of consumers and their mental health case managers as to the nature of the work they were doing together. In particular, the study aimed to explore perceptions of both parties concerning the use of a collaborative recovery framework. More specifically, the aims of the study were:

1. To develop and pilot a consumer and case manager questionnaire based on those aspects of support and treatment which have been identified in the literature as facilitating recovery, to determine if those aspects are of importance to consumers.
2. To evaluate the reliability of the questionnaire and its suitability for use as a scale.
3. To evaluate the validity and utility of the questionnaire in measurement of the perceptions and priorities of different stakeholders in the mental health service delivery process.

The research design required the development and pilot cross-sectional administration of a questionnaire to dyads of consumers and case managers. This design, using a different questionnaire, had been previously tested in a study of case management practices (Hemming & Yellowlees, 1997).

### **Method**

#### ***Sample***

The study took place within the public mental health service of a major regional centre in North Queensland. Case managers with at least six months of experience with the service were approached to participate in the study. Four case managers comprised the final sample (a social worker, a psychiatric nurse, and two occupational therapists). The small number of practitioners meeting the inclusion criteria reflected a high staff turnover at the time of the study.

Inclusion criteria for consumers participating in the study were: experience of psychotic illness (DSM-IV Axis 1 diagnosis of Schizophrenia, Bipolar Disorder or Schizoaffective Disorder); at least 3 months since last relapse or hospitalisation; and engagement with a case manager taking part in the study for at least six months. A final sample of 15 consumers (7 males and 8 females) was interviewed, representing a 75% participation rate. The age range (20 to 40 years) reflected the sample obtained by Hemming & Yellowlees (1997). Twelve consumers had a diagnosis of schizophrenia/schizoaffective disorder and three had a diagnosis of bipolar disorder. One consumer was of Indigenous background, and one was from a non-English speaking background.

### ***Development of the questionnaire***

Initially, a literature search for tools measuring perceptions of recovery was undertaken. At the time of the research (late 1999 to early 2000) no appropriate measures were identified. The Recovery Interventions Questionnaire (RIQ) was developed from some of the broad areas identified in the literature as facilitating recovery: *Medication use; Spirituality; Knowledge/acceptance of illness; Collaborative treatment planning; Relationships with case manager and service; Strengths-based interventions; Role of self-will and self-monitoring; and Community and personal support* (i.e. the importance of people who stand by the person with mental illness). A block of 5 to 7 questions comprised each of these scales, which were presented sequentially. Most of the total 50 questions were linked to a Likert-type Scale response of Strongly Agree (4), Agree (3), Disagree (2), or Strongly Disagree (1), such that higher scores indicate greater agreement.

There were no particular factors that determined the order of presentation of each block of questions, except for one question. This related to the area of 'Community and personal support', which examined use of and experience with community-based groups and agencies. Because this question had a different answer format than other questions (a checklist-style table format involving rating scales), it was placed last on the

RIQ form (see Appendix 1 for the consumer version of the questionnaire).

Throughout the RIQ, the use of the terms 'mental illness' or 'mental disorder' were replaced by 'symptoms'; it was felt that using the alternative terms is stigmatising and may discourage some respondents who may not wish, for a variety of reasons, to be labelled as 'ill'.

The initial draft of the RIQ was trialled with an unmatched sample of four consumers and three case managers. The consumers were volunteers from a non-government sector consumer organisation. The case managers were from a separate Community Mental Health Service and all were psychiatric nurses. Some minor rewording, and the introduction of skip structures resulted from the pre-trial, as did the decision to remove the 'Uncertain' category of the Likert scale, due to a high number of responses (up to 25%) recorded in the consumer trial. The consumer questionnaire was then developed to pilot form. Based on the areas outlined in the consumer RIQ, a corresponding questionnaire was developed for case managers.

### ***Procedure***

The four case managers who met the study criteria were asked to select consumers from their caseload who met the criteria of diagnosis and period of recovery since last episode of illness. Those consumers were asked by their case managers to take part in the study.

Case managers answered a questionnaire on each of the consumers in their caseload, identified by a number on the top of each form as well as their own case manager number. Consumer forms also had identifying numbers for case manager and consumer. Questionnaires were completed independently and returned directly to the investigator. Neither group was aware of the answers of the other group, and all information related to cross-referencing was stored separately to the completed forms.

### ***Data analysis***

Visual inspection of the data revealed that the four case managers made independent responses

in relation to each of the consumers in their caseload. Following the methodology of Hemming and Yellowlees (1997) (with six case managers and 25 consumers) it was decided to treat each case manager response as an independent observation, resulting in a total of 15 paired questionnaires. Paired comparison t-tests were used to analyse sub-scales with interval data characteristics. Wilcoxon signed ranks tests were used to analyse individual items with ordinal data characteristics.

### ***Ethics approvals***

This project met the requirements of the Ethics Committees of both the District Health Service and the University of Queensland. Participants were read an information sheet on the study, which was then retained by them, and signed a consent form.

## **Results**

### ***Internal consistency of questionnaire sub-scales***

Reliability (internal consistency) was evaluated for five of the eight sub-scales (skip structures within the questionnaire resulted in high rates of missing data for three sub-scales). Sub-scales for *Medication use* (alpha = .72), *Spirituality* (alpha = .71) and *Relationship with the Case Manager and Service* (alpha = .76) were found to have acceptable internal consistency. The remaining sub-scales of *Strengths-based interventions* and *Self-will and self-monitoring* returned marginal reliability scores (.64 and .69 respectively). Internal consistency was judged to be sufficient to warrant calculating sub-scale totals, permitting comparison between case manager and consumer scores on a more limited set of variables than would be the case if items were compared individually.

### ***Consumer and case manager scores on reliable sub-scales***

All case managers and consumers responded to all the items on the *Medication use* sub-scale. Case managers had a higher mean total score for the medication sub-scale than did the consumers (17.4 and 15.2 respectively,  $t=2.4$ ,  $df=28$ ,  $p<0.05$ ), suggesting that case managers rated their role in assisting consumers with medication more highly than did consumers. Individual item analysis, using Wilcoxon signed ranks test suggested that case managers were more likely to think that they listened to consumer's medication worries than were consumers ( $p<0.05$ ), and that they were also more likely to think that they had discussed medication side effects than were consumers ( $p<0.05$ ).

There was sufficient data to enable meaningful comparisons of consumers and case managers in respect of the *Strengths-based interventions* sub-scale. A comparison using paired comparison t-test indicated a trend towards case managers being more likely than consumers to indicate that strengths-based interventions were being used ( $t=1.9$ ,  $df=28$ ,  $p=.007$ ).

Comparison of sub-scale scores for *Relationship with the case manager and service* using paired comparison t-tests showed that mean total scores for case managers were significantly higher than those for consumers (21.1 and 18.9 respectively,  $t=2.3$ ,  $df=28$ ,  $p<0.05$ ).

Individual item comparisons, using Wilcoxon signed ranks test were made for items that fell outside the reliable sub-scales. Items that showed significant differences between case managers and consumers are set out in Table 1. There was a consistent trend for case managers to rate service provision higher than consumers, however consumers showed stronger agreement that when unwell they are able to take effective action to get through a crisis.

**Table 1. Questionnaire items rated higher by consumers or case managers**

Sub-scales Items	Consumer Mean	Case Manager Mean	Wilcoxon Z	p
<b>Self-monitoring</b>				
Q35 Consumer responds effectively to crisis	3.1	2.5	2.1	< 0.05
<b>Medication use</b>				
Q2 Consumer aware of side-effects	2.8	3.6	2.1	<0.05
Q4 Case manager attentive to consumer concerns	3.1	3.7	2.3	<0.05
<b>Strengths-based interventions</b>				
Q28 CMHS provides opportunities to develop skills	2.0	2.9	2.3	<0.05
Q30 Case manager encourages abilities	2.9	3.5	2.1	<0.05
<b>Relationship with case manager and service</b>				
Q40 Case manager will provide outreach visits	3.0	3.7	2.1	<0.05
Q41 Case manager contact increases in unwell times	3.2	3.8	2.1	<0.05
Q42 Case manager would visit consumer in hospital	3.2	3.8	2.1	<0.05

Scoring: 1=Strongly disagree, 2=Disagree, 3=Agree, 4=Strongly Agree.

With respect to the first research question posed by this study, the findings were consistent with previous research on consumer perceptions of recovery. The majority of consumers indicated that medication was helpful to them (73.3%), spirituality was of importance (80%), spiritual beliefs helped them to recover (75%), and knowing about the causes of their illness was important (93.3%) (cf Sullivan, 1994). They also recognised that they had skills and abilities (86.6%), (cf Rapp & Wintersteen, 1989), and that they could talk easily with their case manager (93.3%) (cf Hemming & Yellowlees, 1997). Consistent with findings by Lang et al. (1999) that consumers experienced less difficulty with psychiatric symptoms than their case managers perceived, consumers in this study agreed that they could respond to signs of illness (73.3%) and take effective action in a crisis (86.6%).

## Discussion

The issue of consumer recovery is a topical and important one, which few other Australian studies have addressed. The study described here has several limitations that affect the extent to which the findings can be generalised. A much larger sample and a full reliability and validity study are required to further develop this measure, as well as confirmatory factor analysis

to assess the factor structure. There are also limitations in the selection of participants and within the questionnaire design and administration. As the case managers selected the consumer sample for this study, it is possible that an element of bias was involved, for example consumers seen as less capable or progressing slowly in their recovery may not have been included. Similarly, consumers who were unwell at the time of the project may also have been excluded, even though the criteria specified that they should be able to give informed consent, rather than present as 'well'. These factors, however, would tend to contribute towards results that showed stronger concordance between case managers and consumers.

Comparisons with similar research proved difficult as there are few other studies using this methodology. The results were compared to a study of consumer and case manager perceptions of case management by Hemming and Yellowlees (1997), who found strong agreement between similarly-paired groups (6 case managers and 25 consumers) in relation to services delivered and received across all thirteen components of their questionnaire. In contrast, the present study found significant differences across three of the five reliable sub-scales, as well as significant differences on

several individual items within the other sub-scales. This suggests that the items in the present questionnaire may have investigated areas where differences were more likely to occur between the two groups, that the instrument itself was more sensitive to eliciting differences, or that the language of the RIQ was less technical.

The RIQ was also useful in highlighting differences in perceptions of service delivery. Overall, in the sub-scales where reliability was established, case managers tended to rate aspects of their practices higher on a number of items (see Table 1), and inconsistencies between the ratings of the groups were also evident in items within the sub-scales with marginal reliability results. These included aspects of medication use and education, outreach and follow-up services provided by case managers, psychoeducation, encouragement of personal strengths, and provision of opportunities to develop existing consumer skills.

Other results indicated some perceived deficiencies in service delivery, but were unable to be meaningfully quantified. The sub-scale of *Collaborative treatment planning* returned insufficient data to be included in reliability testing, largely because a very small number of consumer responses indicated awareness of an individual treatment plan, despite the emphasis within the current National Standards (National Mental Health Strategy, 1996) that these be developed collaboratively. This reflects the findings of the Mental Health Council of Australia (2000), mentioned earlier, that consumer participation in treatment plans has not been implemented.

This paper has presented one research approach to exploring consumers' and case managers' perceptions of recovery. The outcomes of a larger study may assist in establishing the directions in service delivery and case management practices that are necessary to establish a more collegiate and collaborative working relationship between consumers and their case managers. There is also a need for further debate and investigation of the most meaningful ways to quantify consumer recovery processes. Consumers, for example, have expressed a degree of dissatisfaction with the

appropriateness of quantitative measurement scales (Stedman et al., 1997). Some of the more elusive components of recovery that were not included in this study, such as empowerment, may be more appropriately researched in a qualitative study.

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### Appendix 1: Items included in the consumer version of the Recovery Interventions Questionnaire

Unless otherwise indicated, items have a response scale of: *Strongly Agree / Agree / Disagree / Strongly Disagree*. This is a modified version of the questionnaire. Permission to use or reproduce must be sought from the authors.

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1. My case manager has explained to me how my medication can help control my symptoms.
  2. My case manager has discussed with me all the possible side effects of the medication I take.
  3. I can discuss with my case manager any problems I may have with my medication.
  4. My case manager listens when I have worries about my medication.
  5. I feel that medication is helpful.
- The next five questions ask about spiritual beliefs, which include religious beliefs and personal beliefs, which give meaning and purpose to life.*
6. Spiritual beliefs are important to me.  
(Go to Question 11 if Disagree/Strongly Disagree)
  7. My spiritual beliefs help me to stay well.
  8. My case manager knows that my spiritual beliefs are important to me.
  9. My case manager seems to be comfortable discussing spiritual matters.
  10. I have discussed my spiritual beliefs with my case manager.
  11. It is important for me to know what causes the symptoms I experience.
  12. I believe my symptoms are caused by a chemical imbalance in the brain.
  13. My case manager has given me an explanation of the causes of my symptoms.  
(Go to Question 15 if Disagree/Strongly Disagree)
  14. I have found this explanation helpful to me.
  15. My case manager has given me information about the different ways of dealing with my symptoms.  
(Go to Question 17 if Disagree/Strongly Disagree)
  16. I have found this information has helped me choose the best way to handle my symptoms.
  17. My case manager has given me information about the extent to which other people in the community experience the same symptoms as myself.  
(Go to Question 19 if Disagree/Strongly Disagree)
  18. I have found this information to be helpful.
  19. I understand how the symptoms I experience affect my daily life.
  20. My case manager and I have a written Care or Treatment Plan to deal with my problems.  
*Yes / No (if No, go to Question 27)*
  21. My case manager has given me a copy of my plan.  
*Yes / No*
  22. My case manager and I have identified all my needs in the plan.
  23. The plan sets out goals, timeframes and what each of us will do, to meet my needs.
  24. This plan has been developed by:  
*My case manager entirely*  
*Both, but mostly my case manager*  
*Both equally*  
*Both, but mostly me*  
*Entirely me*
  25. Changes to my plan have been the responsibility of:  
*My case manager entirely*  
*Both, but mostly my case manager*  
*Both equally*  
*Both, but mostly me*  
*Entirely me*
  26. Other people, such as my family and friends, have been involved in my plan as well.  
*Yes / No*
  27. I recognise that I have skills and abilities in certain areas
  28. As a result of my involvement with the Community Mental Health Service, I have been given opportunities to:  
*Develop my skills or abilities*  
*Learn new skills*  
*Both of these*  
*Neither of these*
  29. My case manager recognises that I have abilities and talents.
  30. My case manager encourages me to make use of my abilities and talents.
  31. My case manager has referred me to activities or places where I can follow my interests.
  32. I can name at least 4 early signs that I may be becoming unwell.
  33. I know at least 2 things to do that will help prevent me becoming unwell when I experience early signs.
  34. I will be listened to if I tell my case manager when I am starting to feel unwell.
  35. When I become unwell, I am able to take effective action to get through the crisis.
  36. People who are closest to me understand about my illness and support me through periods of difficulty.
  37. I can talk easily with my case manager.
  38. I feel welcome at the Community Mental Health Centre.
  39. I look forward to my visits to the Community Mental Health Centre.

40. My case manager comes and visits me at home or we meet somewhere else if I do not want to visit the Community Mental Health Centre.
41. If I became unwell, my case manager would spend more time with me.
42. If I were admitted to hospital, my case manager would visit me there.
43. I have been involved in groups at the Community Mental Health Centre.  
*Yes / No (if No, go to Question 45)*
44. The groups I have been involved in have helped me deal with my illness.
45. I have family or relatives who give me support.  
*Yes / No (if No, go to Question 47)*
46. My case manager is aware of the importance of my family and involves them when I need support.
47. I have friends who give me support.  
*Yes / No (if No, go to Question 49)*
48. My case manager is aware of the importance of my friends and involves them when I need support.
49. I have had support from other groups or people that are not part of Community Mental Health Services.  
*Yes / No (if No, this is the final question)*
50. Below are listed a number of community and health services. Please indicate if you have seen any of these services, and how helpful they were. *If you have seen more than one of any type of service (e.g. two doctors, two employment services) please use the one you have had most contact with in the past six months.*

*Tick the Yes or No box, then rate how helpful you feel they were according to the numbers below:*

*1 = Very helpful, made a big difference in my life*

*2 = Helpful, made a lot of difference in my life*

*3 = Helpful, made a little difference in my life*

*4 = Helpful, but made no difference in my life*

*5 = Unhelpful*

*6 = Unhelpful and made me feel worse*

*7 = Undecided*

Health or Community Service	Used by consumer		Rating of helpfulness
	Yes	No	
Doctor or General Practitioner			
Self-help Group (eg GROW, AA)			
Alternative Treatment (eg Naturopath)			
Church or Spiritual Group			
Sporting Group			
Hobby or Interest Group			
Family Support Organisation			
Consumer Organisation (eg SHAC)			
Neighbourhood or Community Centre			
Voluntary Work			
Employment Service			
Housing Service			
Legal Service			
Counselling Service			
Other (list)			