Australian mental health consumers' contributions to the evaluation and improvement of recovery-oriented service provision

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Australian Mental Health Consumers’ Contributions to the Evaluation and Improvement of Recovery-oriented Service Provision

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ABSTRACT

Background: One key component of recovery-oriented mental health services, typically overlooked, involves genuine collaboration between researchers and consumers to evaluate and improve services delivered within a recovery framework.

Method: Eighteen mental health consumers working with staff who had received training in the Collaborative Recovery Model (CRM) took part in in-depth focus group meetings, of approximately 2.5 hours each, to generate feedback to guide improvement of the CRM and its use in mental health services.

Results: Consumers identified clear avenues for improvement for the CRM both specific to the model and broadly applicable to recovery-oriented service provision. Findings suggest consumers want to be more engaged and empowered in the use of the CRM from the outset.

Limitations: Improved sampling procedures may have led to the identification of additional dissatisfied consumers.

Conclusions: Collaboration with mental health consumers in the evaluation and improvement of recovery-oriented practice is crucial with an emphasis on rebuilding mental health services that are genuinely oriented to support recovery.

INTRODUCTION

Research involving consumers in the evaluation of recovery-oriented practice appears rarely if at all in the literature (1). Despite the increasing emphasis on recovery as a guiding vision for mental health service (2-4), few models of care have attempted to operationalize the principles of recovery into practice (5, 6).

The Collaborative Recovery Model (CRM) and associated training program for mental health staff is an example of an early attempt to convert a recovery vision for mental health services into specific principles and practices. This model was developed with a view to bringing together evidence-based practice and constructs consistent with the recovery movement to assist people with chronic and recurring mental disorders to work towards recovery in community mental health contexts (7). A definition of recovery consistent with this model involves “the establishment of a fulfilling and meaningful life and a positive sense of identity founded on hopefulness and self determination” (8, p. 588).

Development of the CRM and its related training program draws on existing evidence from the recovery literature, in particular concepts such as facilitating hope, supporting autonomy, and subjective goal ownership (7). For example CRM training champions the individuality of the lived experience and ownership of the recovery process by the consumer, while recognising that other people, including mental health staff, can support individuals’ recovery processes. A key way in which this is enacted within the CRM is through a focus on authentic, approach oriented goals, collaboratively agreed upon by the consumer and staff. It is known that active goal setting focuses recovery and provides individuals with a sense of what is important and meaningful to strive towards in the future (9). The Collaborative Goal Technology (CGT) was specifically developed with this purpose in mind. Using this tool, staff members are encouraged to assist consumers to identify a personal recovery vision, as well...
as autonomous goals to support them in moving towards a fulfilling and meaningful life (10).

Specifically the CRM consists of two guiding principles: 1) recovery as an individual process and 2) collaboration and autonomy support. It also has four practical components: 1) change enhancement, 2) collaborative needs identification, 3) collaborative goal setting and striving, and 4) collaborative task striving and monitoring. These principles and components form the six training modules delivered to staff as part of the Collaborative Recovery Training Program. Initial training occurred within a two-day workshop, followed by two one-day booster sessions at 6 and 12 months following the initial training (11). There are four specific protocols for staff to follow, which require associated knowledge, skills and particular attitudes in order to work within a recovery orientation. The first skill is motivational enhancement (ME). This involves staff helping the person to identify advantages and disadvantages of specific behavior change in order to assist the person to activate his/her motivational resources to pursue desired life changes. As part of the second protocol staff are encouraged to use the Camberwell Assessment of Need Short Appraisal Schedule (CANSAS) (12) as a precursor to goal setting. It is emphasized that unmet needs are a key source of motivation for individuals and that a negotiated approach to need is helpful. Thirdly, staff are taught to use the CGT (10) in a collaborative manner to assist consumers to elicit and document a meaningful recovery vision and a maximum of three measurable and manageable goals. Finally staff members receive training in flexibly reviewing, designing and assigning tasks related to goals. This includes helping individuals identify and overcome obstacles that may hinder goal progress. See Oades et al. (7) for further information related to staff training.

The CRM is an example of a model that creates the possibility for recovery-oriented practice in mental health services. However, this is not enough. There is a clear need to examine consumers’ perceptions regarding all aspects of the CRM, including how the model is experienced when working with staff in service settings (13). For example, from consumers’ perspectives is recovery progressing? How is it being supported? How is it being hindered? To what degree do staff members work consistently with this particular recovery oriented practice model? How can the CRM be improved to better support an individual’s recovery journey?

This study examined the experiences of consumers working with staff trained in the CRM, with a view to obtaining practical recommendations for improvement of the model and its use and delivery in mental health services into the future. This is important in terms of recovery because, after all, recovery is the lived experience of the consumer. However, the consumer’s voice is not the only legitimate one. Mental health staff and family members’ viewpoints are also likely to be important within the context of a recovery oriented mental health system (9, 14). Staff members’ views of the CRM have previously been examined, in addition to consumers’ in a related study (13). Family members’ views have not been examined but remain a worthwhile direction for future research.

An emphasis on service improvement in this study is consistent with contemporary conceptualizations of evaluation, such as formative evaluation (15). Some authors have suggested that consumers may place particular value on service improvement (16) which may be linked to their desire to assist others with mental illness (17). Focus group methods have been recognized as particularly beneficial when engaging participants in quality improvement and action based research (18, 19).

**METHOD**

**PARTICIPANTS**

All consumers in this study were participants in a larger study, the Australian Integrated Mental Health Initiative High Support Stream (AIMhi HSS) project which involved the evaluation of the impact of the CRM on the recovery of adults with chronic and recurring mental disorders by way of a multisite study in four government and five non-government organizations within New South Wales, Queensland and Victoria, Australia. Research sites were randomly assigned to either an immediate CRM staff training or one-year delayed training condition. Inclusion criteria for consumers included a diagnosis of schizophrenia, schizoaffective disorder, bipolar disorder or Major Depressive Disorder with psychotic features of at least six-months duration and high support needs (identified as five or more total needs using the Camberwell Assessment of Need Short Appraisal Schedule). Individuals with dementia, severe mental retardation or brain injury were excluded (7). A total of 242 consumers and 114 staff agreed to participate in the AIMhi HSS project.

Eighteen consumers participated in this study from New South Wales and Queensland, Australia. Participants were attending a public mental health service in regional Queensland (N=4) or a regional or rural site of a non-government organization in New South Wales (N=7) or
Queensland (N=6), Australia. Eleven (61%) participants were female and seven (39%) were male. Participants had a mean age of 38 years (SD of 5.9 years), comparable to the larger sample of participants in the AIMhi HSS project (M=39.9, SD=12.5, at baseline).

Diagnostic information was collected from clinicians indicating that 50% of the sample met the diagnostic criteria for schizophrenia (n=9), 22.2% schizoaffective disorder (n=4), 22.2% depressive psychosis (n=4), and 5.6% bipolar disorder (n=1). Three participants were identified and agreed to take part in focus groups, with a particular focus on their critique of the CRM, or their experience of this model as received in services.

**PROCEDURE**

Structured focus group protocols were developed including a protocol for group facilitators outlining key areas to discuss with focus group participants and power-point slides to support and complement the verbal presentation/discussion. Participants also received a one-page handout summarizing key findings from two earlier studies undertaken with consumers evaluating the CRM and a CRM diagram for reference during meetings. Focus group protocols were distributed to four consumer researchers for review and comment. Feedback offered guided further refinements.

Focus groups commenced with a brief overview of the CRM and an emphasis on topics covered during staff training. Facilitators also briefly described to group members relevant issues regarding limited exposure to practical components within the context of the AIMhi HSS (i.e., statistics regarding what people actually received in practice with a focus on practical components). Facilitators then raised relevant findings for discussion with a focus on unhelpful aspects, areas of concern and suggestions for improved practices. The starting point for this discussion was drawn from key findings from two earlier studies. This included a brief questionnaire administered to 92 consumers, as well as 22 in-depth interviews undertaken with consumers taking part in the AIMhi HSS. Participants were therefore encouraged to reflect on other consumers’ experiences of the CRM, as well as offering their own experiences of working with CRM trained staff.

Participants were provided with detailed information about this study and were required to sign formal consent, as approved by the relevant ethics boards. Focus group meetings were held in July and August 2007. The first meeting was held in Queensland, Australia and was attended by seven consumers. The second group was held in New South Wales, Australia and was attended by 11 people. Group meetings ran for approximately 2.5 hours including a 30-minute refreshment break. Two paid consumer researchers co-facilitated each focus group meeting in collaboration with the primary researcher. All consumer researchers employed as co-facilitators had existing experience in relation to research activities and prior exposure to the CRM. All co-facilitators attended a training session.

**DESIGN AND ANALYSIS**

Maximum variation sampling was employed in this study. A key selection criterion was to recruit people who were critical of the CRM, or certain aspects of it. Clinicians and research assistants working within the various organizations nominated people they believed met these selection criteria. There was an effort to target people who had ceased their involvement in the AIMhi HSS project and, where possible, clarifying reasons for their departure. This involved staff speaking directly to consumers they had been working with to clarify more about their experiences and to ascertain whether they were willing to be interviewed. An advertisement was also placed in the CRM newsletter, which was posted to all consumers participating in the AIMhi HSS project. There was also an attempt to balance gender and age of participants. An additional focus was on recruiting people from both public mental health services and non-government organizations in different states of Australia and across the range of diagnoses participating in the larger project.

Focus groups were audiotaped and transcribed verbatim. Thematic analysis was undertaken and key themes obtained from focus group data were identified using the following steps: 1) Familiarity with the focus group data was obtained by reading and re-reading transcripts several times; 2) Focus group transcripts were reviewed in turn and group members’ responses to the areas outlined in the focus group schedule were located within the transcripts. These themes were summarized for ease of reference. Example quotes were also located and included; 3) Transcripts were checked for other relevant information that fell outside the areas for discussion identified on the focus group schedule, but remained relevant for the improvement of the CRM and associated staff training; and 4) Summaries for the two focus groups were then cross-referenced to compare whether findings were similar for meetings held in New South Wales and Queensland, Australia.
RESULTS

FINDINGS AND RECOMMENDATIONS

A summary of key findings from focus groups is available in Table 1. This table identifies seven key concerns identified by consumers, examples of relevant quotes, possible avenues for improvement and an overview of broader implications for recovery oriented practice and mental health service delivery. Concerns and recommendations are discussed further below and hold relevance not only for improvement of the CRM, but in many instances have broader applicability to recovery-oriented practice. For example, goal striving and homework are practical activities, which may already be utilized by mental health staff. This study highlights some consumers’ concerns around these practices, which may help inform the way in which staff can more effectively engage in such activities with consumers in the future.

1. EQUIVALENT CRM TRAINING SHOULD BE DEVELOPED FOR CONSUMERS

There was a perception among some consumers that the CRM was not presented to consumers in an appropriate manner that maximized its appeal. A number of people spoke about the emphasis on paperwork and the sense that the model was something that they had to do. One suggested avenue for improvement was to introduce consumers to the CRM within a peer-group setting. Presently the standard CRM two-day initial training package and booster sessions mentioned above are available for mental health staff. An equivalent training program should be offered to consumers. Mental health consumers should ideally facilitate training. This may assist in enhancing consumer ownership and responsibility at the outset.

2. IMPROVED EMPHASIS SHOULD BE PLACED ON ACCURATELY CONVEYING THE MESSAGE OF RECOVERY TO CONSUMERS. FOR EXAMPLE BY WAY OF IMPROVED STAFF TRAINING AND/OR A PEER-RUN GROUP SETTING TO FACILITATE INCREASED AWARENESS OF IDEAS REGARDING RECOVERY

Some participants raised their concern that mental health staff had spent an inadequate amount of time, if at all, discussing and orienting them to the concept of recovery. In addition a number of consumers participating in interviews as well as focus groups expressed confusion with the term recovery. For example, one person said that the word recovery was “foreign” to him, stating, “I’ve heard the word recovery before, but what it actually means or is supposed to be I didn’t know” (participant, NSW group).

3. ADDITIONAL INTERVENTIONS SHOULD BE DEVELOPED AND OFFERED TO ADDRESS DIFFICULTIES REGARDING TRANSFER OF TRAINING OF CRM INTO PRACTICE IN MENTAL HEALTH SERVICES

Some focus group participants discussed clinicians’ negative attitudes towards the CRM, in particular written documentation or “paper work” requirements for goal and homework sheets. These perceived negative attitudes in turn influenced consumers’ perceptions of these practical aspects. One person said, “if they are kicking and screaming we’re not going to turn around and say, well hold on a second that is a good idea” (participant, QLD group). Another consumer raised concern that perceived pressure placed on staff to complete written documentation in some instances flowed through to the consumer. A related concern echoed by several participants was their belief that staff might not have been receiving adequate ongoing support, following their initial training in the CRM.

Future changes to staff training and support procedures should be undertaken in consultation with service providers and should include exploration of key barriers to implementing the CRM in practice settings, as perceived by staff. Key barriers identified by staff participating in the AIMhi HSS study were perceived to be “institutional constraints” such as negative attitudes towards the CRM and perceived pressure placed on staff to complete written documentation. These findings highlight the importance of addressing these barriers to improve the transfer of training from the CRM into practice settings.
<table>
<thead>
<tr>
<th>Summary of &quot;unhelpful&quot; area or concern</th>
<th>Example of relevant consumer quotes</th>
<th>Possible directions for improvement</th>
<th>Broader implications for recovery-oriented practice/service delivery</th>
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<tr>
<td>1. CrM not presented to consumers in an appealing manner from the outset</td>
<td>“You present it to the consumers first... we all get together and get excited about it and then the support worker comes along...the way I received it is that she landed on my doorstep with these big fat books and just basically said this is the way we have to do it” (participant, QLD group)</td>
<td>1. Introduce and orient consumers to the CrM within a peer-group setting 2. Develop equivalent CrM training for consumers on commencement in the program (presently CrM training offered to staff only). Mental health consumers should facilitate training</td>
<td>Initial training in recovery-oriented practice should be offered to both consumers and mental health staff. This is likely to assist in empowering consumers from the outset and encouraging development of more equal and collaborative working relationships</td>
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<td>2. Some mental health staff’s inadequate discussion with consumers around recovery</td>
<td>“It was a bit like the birds and the bees scenario (reflecting on staff discussion of recovery)...I got the talk but it wasn’t a warm and friendly discussion around who you might marry or whatever, it was just the talk” (participant, QLD group)</td>
<td>1. Introduce consumers to recovery within a peer led group setting on commencement with model (overlap with point 1 above) 2. During staff training emphasis on sharing and discussing concept of recovery with consumers/ various avenues to convey this message, e.g., consumer stories/videos</td>
<td>Knowledge of “recovery” should not be assumed for staff or consumers. This area should be explicitly emphasized during recovery-oriented training. Staff should be afforded with opportunities to practice conveying the message of recovery to consumers using various mediums</td>
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<td>3. Perception that some staff had negative attitudes towards the CrM</td>
<td>“If a support worker makes you understand they don’t agree with the paperwork you’re going to do oh good, I’ll get out of this, because they don’t want to do it anyway. So maybe that is something in your training that has to be changed” (participant, NSW group)</td>
<td>1. Improve ongoing training and support procedures offered to staff beyond the 2-day initial training and 1-day booster sessions</td>
<td>Employment of multiple strategies may support improved dissemination of recovery-oriented practice in service settings, e.g., support of management and team leaders, linking of research with the “mission” of organizations and workplace coaching</td>
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<td>4. Existing format of goal and homework sheets may place too much emphasis on written documentation for some people</td>
<td>“I hate reading. I just usually go through it and write down whatever and ignore it... I find that annoying too much reading” (participant, NSW group)</td>
<td>1. During CRM training emphasize alternate methods to written documentation when communicating goals and homework 2. During redesign of goal and homework sheets into a personalized diary/book encourage alternate expression such as by way of illustration/collage/photography</td>
<td>Staff assisting consumers to set goals in line with their preferred life directions should encourage various means of communication, beyond traditional written expression. For example use of photography, drawing, collage as preferred by the individual</td>
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<td>5. Perception that goal and homework sheets owned by mental health staff, as opposed to consumers</td>
<td>“You wanted to get your own place or something just cut a picture from the newspaper of a house that you love...I know it’s a method but I don’t think people use it enough” (participant, QLD group)</td>
<td>1. Development of a consumer owned personalized book/diary to document goals and homework and relevant aspects of recovery journey</td>
<td>Goal setting tools and homework should be designed into a format where consumers are encouraged to take personal ownership over such documents. Individual sheets distributed by staff are not preferred. A possible alternative includes a journal/book that is owned and personalized by consumers. Consideration of staff reporting requirements is important but should not be the main factor guiding design decisions</td>
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<td>6. Difficulty regarding goal striving during periods of illness</td>
<td>“When you do something that’s your own... your own diary or your own journal it’s very different then if you do something like that (goal and homework sheets) which looks so official” (participant, QLD group)</td>
<td>1. Staff should discuss exacerbation of mental illness as one possible barrier to goal striving and negotiate an individual plan as to how to proceed, in the event this occurs 2. The area outlined above should be discussed with staff during CRM training</td>
<td>Staff working with consumers to set life goals should consider discussing an exacerbation of symptoms as one possible barrier to goal striving. A personal approach regarding how to proceed in the event that this occurs can be negotiated where appropriate. This may help allay some consumers concerns in this area</td>
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<td>7. The use of word “homework” and “recovery vision” viewed as inappropriate for some consumers</td>
<td>“You’re an adult, it’s really offensive for someone to tell an adult to do their homework” (participant, QLD group)</td>
<td>1. The words “homework” and “recovery vision” may not be preferred by some consumers. Staff should discuss a personally appropriate and meaningful term.</td>
<td>Staff should be aware of their use of clinical language and possible impact on individual consumers. For example some persons may consider the terms “homework” and “recovery vision” inappropriate. Alternative personally meaningful terms should be identified where relevant. For example possible suggested alternatives include mini goal, task (when referring to homework) and life vision, life direction (when referring to recovery vision)</td>
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Concerns were raised by some consumers regarding the perceived ownership of goal and homework sheets/books by case managers, as opposed to consumers. The current format for the CRM (separate books containing goal and homework sheets kept by staff, with single sheets provided to consumers on completion) does not seem to support consumer ownership or responsibility over this process.

A recommended way of addressing this concern offered and supported by group participants was to have a book or diary that was owned, kept and written in by the consumer where they could record their goals, homework and other relevant information. One consumer when describing the benefits of a “book” format said, “just by writing your goals down and reflecting on them in your own words it's healing because you gain that sense of autonomy back” (participant, QLD group). Other group members supported this perspective, for example describing such a format as “empowering.”

This finding has broader relevance to mental health staff assisting consumers with goal setting and homework activities within the context of supporting their recovery. Consideration should be given to enhancing consumer ownership and responsibility not only at the process level when engaging in goal and homework activities (for example in setting and reviewing these activities), but also at a more practical level in terms of any tools/forms used and how and where this information is documented and kept.

**4. Consumers should be encouraged and provided with options to express their goals and recovery visions using alternate mediums such as drawings, photographs and pictures as desired**

Some consumers expressed concern that goal and homework sheets placed a heavy emphasis on a written format, identified as an unfavorable means of communication for some people. For example, it was suggested that the existing format might be inappropriate for people with reading or writing difficulties and/or for people who had preferences for other forms of communication such as in the visual, rather than verbal domains. This should be considered during redesign of goals and homework into a book format (see point 5). Staff should be encouraged to consider and discuss alternate methods of communicating goals and homework with consumers (such as through illustration, collage or photography).

This finding has broader relevance to mental health staff outside of the CRM program. Goal setting is a common practice in case management and mental health rehabilitation settings (24). Furthermore, goal setting is known to be a key factor in supporting recovery, providing a source of hope and meaning for individuals’ recovery journeys (8).

**5. Goal and homework sheets should be incorporated together into a book-type format that is owned and can be personalized by mental health consumers**

Concerns were raised by some consumers regarding
is related to consumers’ level of symptom distress. For example when symptoms are less distressing, consumers are better able to make progress towards their goals (24). Therefore the severity of illness and symptomology would likely influence consumer and staff decisions relevant to this aspect. It is recommended that staff discuss the possibility of becoming unwell with consumers as one possible barrier to goal striving. This may help allay concerns, in particular if an individualized plan is discussed as to how consumers would prefer to proceed in the event of becoming unwell or experiencing an exacerbation of their symptoms.

7. SOME CONSUMERS MAY VIEW THE TERMS “HOMEWORK” AND “RECOVERY VISION” AS INAPPROPRIATE. STAFF SHOULD ASSIST INDIVIDUALS TO IDENTIFY LANGUAGE THAT IS PERSONALLY MEANINGFUL/APPROPRIATE

Consumers’ concerns with the term homework appeared to focus on issues to do with perceived lack of choice and paternalism implied by the use of this term. Consumers taking part in focus group meetings used words such as “disgusting,” “offensive” and “condescending,” when discussing use of the term. For some participants the term conjured up strong negative associations with experiences at school, where they were told to do something, as opposed to being involved in this process. Consumers suggested a range of alternate terms that could potentially replace the term homework such as goal work, goal tasks, short-term goal and mini goal.

Findings from interviews and focus groups also indicated that some participants had concerns with the use of the term “recovery vision” (used within the context of the CGT). During interviews three people used the term “life vision,” as opposed to the term “recovery vision” when discussing this aspect of the CGT. The term “life vision” appears more consistent with the everyday language used by consumers. It may also assist in shifting consumers to focus beyond their illness, to their broader life goals and visions. The use of the term “life” within this context is also likely to be more consistent with language used by the general population when discussing their goals and future directions. Staff engaging in discussions with consumers around their larger life directions would benefit from identifying a term appropriate to the individual. For example, terms such as “life vision,” “life direction,” “life dreams,” “valued direction,” or whatever provides most meaning for the person.

These findings have broader relevance in terms of encouraging mental health staff to be aware of and to critically reflect on their own use of language, within a recovery context. In particular it is recommended that the term “homework” be used with caution and that personally appropriate and meaningful terms be identified in collaboration with individuals.

LIMITATIONS

A limitation of this study was the purposive sampling strategy employed when attempting to identify consumers with “unhelpful experiences” with respect to the CRM. Some participants in the AIMhi HSS study ceased involvement, or “dropped out” in the early stages of commencement in the project. While procedures were put in place retrospectively to examine “drop out” lists, establish reasons for leaving the project (where available) and to contact the person to enquire as to their experiences with the model, this was not always possible. Ideally a procedure would have been implemented to follow up participants as soon as they “dropped out” of the AIMhi HSS to investigate their experiences of the CRM (and where appropriate to invite them to take part in focus groups). Improved processes may have led to identification of additional dissatisfied consumers. Furthermore other consumers may have remained dissatisfied with the CRM but may have not been comfortable sharing their experiences. It is entirely possible that findings may not be representative of all consumers from the AIMhi HSS project who were dissatisfied with the model.

The nature of this study, with an emphasis on purposive sampling meant that relatively small numbers of consumers participated (n=18 from a total sample of 242 consumers participating in the AIMhi HSS project). This limitation was addressed somewhat within the context of a related study where larger numbers of consumers (n=92) provided feedback on their valuation of practices consistent with the CRM by way of a brief structured questionnaire. Findings indicated that the vast majority of consumers tended to rate all aspects of the CRM as important in terms of assisting their recovery (13). In addition interviews were conducted with 22 consumers from the AIMhi HSS project, the results of which informed the protocol for this study (25). Hence, this study should be considered within the context of these two related studies, which helped inform the protocol for focus group meetings.

A further limitation of this research is that appropriateness of consumer recommendations ideally would have been discussed in direct collaboration with other relevant stakeholders including mental health staff and management.
While consumer researchers were involved in this research to some degree (including the review of focus group protocols and as co-facilitators of focus group meetings), some limitations existed in terms of available time and resources. Ideally collaboration with consumers would have occurred extensively at each level of the research process. Evaluation models aligned with collaborative approaches to evaluation may provide guidance for future research in this area such as participatory action research, empowerment evaluation (26) and user focused monitoring (27).

CONCLUSIONS

Findings from this study indicate that consumers wanted to be more empowered and involved in the use of the CRM from the outset. For example through an equivalent training/introductory session, a peer led group to introduce and share experiences of recovery and use of a handheld diary to record goal striving to be personalized and owned by consumers. Such directions around empowering consumers to take more ownership and responsibility for usage of the model and hence their own recovery, may also hold promise for addressing difficulties regarding transfer of the CRM from theory into practice within mental health service. Genuine collaboration between consumers and researchers in the evaluation and improvement of recovery oriented practice is likely to assist in moving beyond rhetoric, to developing services that truly support individual recovery journeys.

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