Measuring Recovery in Mental Health Services

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ABSTRACT

An international policy goal is to orientate mental health services around the support of "recovery": the development of new meaning and purpose in one's life, irrespective of the presence or absence of symptoms of mental illness. Current progress towards a recovery orientation in mental health services is summarized, indicating that pro-recovery policy is in advance of both scientific evidence and clinical practice. Key evaluation challenges are outlined, and indicators of a recovery focus are described. These include quality standards, consumer-clinician interaction styles, and belief and discourse markers. This underpins a proposal for a new approach to service evaluation, which combines attainment of objectively-valued social roles and of subjective-valued personal goals. This approach has applicability as a methodology both for clinical trials and routine practice.

INTRODUCTION

In this article we discuss evaluation of recovery in mental health services. We start by describing what is meant by recovery, and characterizing international progress. We then identify current tools, and make proposals for future research strategies. Finally, we make a specific proposal for an evaluation strategy for use in mental health services, and explore the research and clinical implications.

WHAT IS RECOVERY?

The experience of mental illness *from the inside* has become increasingly visible in the past few decades (1). Individuals describe what their life is like with the mental illness, and what helps in moving beyond the role of a patient with mental illness (2). Building on these ecologically valid accounts, there has been a recent transition towards synthesizing these individual accounts to identify group-level processes and components of recovery (3, 4). One understanding of recovery which has emerged from these accounts emphasizes the centrality of hope, identity, meaning and personal responsibility (5). We will refer to this understanding of recovery as personal recovery, to reflect its individually defined and experienced nature (6).

The most widely used definition of personal recovery in international policy in the English-speaking world comes from Bill Anthony: *a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness* (7). This understanding of recovery contrasts with traditional clinical imperatives – which we will refer to as clinical recovery – which emphasize the invariant importance of symptomatology, social functioning, relapse prevention and risk management. Personal recovery and clinical recovery are different (8). Personal recovery is commonly understood as a process, can best be judged by the individual service user, for some people does not involve symptom reduction, and may not be due to the actions of mental health services. Clinical recovery is commonly understood as an outcome, is a judgement by an observer, and places great emphasis on symptom reduction and effective treatments by mental health services. To note, this distinction has been referred to by other writers as recovery "from" versus recovery "in" (9); clinical recovery versus social recovery (10); scientific versus consumer models of recovery (11); and service-based recovery versus user-based recovery (12). What is common across these different defini-

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tions is a re-orientation from patient to personhood, a re-orientation of valued knowledge and expertise, and partnership and negotiations in decision-making (13). Personal recovery is the focus of this article.

PROGRESS TOWARDS PERSONAL RECOVERY

We now briefly review the extent to which mental health services internationally are oriented towards personal recovery, using as an organizing framework three proposed levels for characterizing the mental health system: the country / regional level; the local level; and the person level (14).

At the country / regional level, personal recovery is the guiding vision for mental health policy throughout the English-speaking world. Supporting recovery is a central aim of mental health policy in the U.S.A., Canada, New Zealand, Australia, Ireland, Scotland and England and Wales. In addition, it is developing as an influence on policy in the German-speaking world (15), and the relevance of recovery ideas in Israel are now being considered (16). There has been a parallel development of interest in personal recovery by the profession of psychiatry (17, 18), and in England also by other professional groups such as occupational therapists (19) and mental health nurses (20).

At the local level, there has been much less progress towards a recovery orientation in how mental health services are actually delivered (21). Several blocks to developing a recovery orientation can be identified (22). For example, there is a sociopolitical expectation that the mental health system will prevent tragedies, especially homicides. This expectation is widespread, even though the linkage of mental illness and violence is not empirically justified (23). The resulting risk management climate defines risk as something to be avoided, rather than necessary for personal growth. This leads to recovery-hindering practices which place "*people in a protective bubble, shielding them from their community and ultimately from their future*" (24). Positive risk-taking in the context of supportive professional relationships is possible and more supportive of recovery than a focus on risk avoidance (25). However, the implementation block we will focus on relates to research. There is a clear need for high-quality evaluative research which investigates the impact of a recovery orientation at a local level (26).

At the person level, the central message to emerge from qualitative syntheses of recovery narratives is that recovery is individual. Opinions in the consumer literature about recovery are wide-ranging, and cannot be uniformly characterized. This multiplicity of perspectives in itself presents a challenge for mental health services – no one approach works for everyone. There is great variation within and between individuals (27). Within individuals, what promotes recovery at one time in their life (such as active involvement from mental health services) may hinder recovery at another. Between individuals, there is great variation in pathways to recovery, with many finding that they experience recovery despite rather than because of mental health services (3, 12, 28). If mental health services are to be focussed on promoting personal recovery, then this means there cannot be a single recovery model for services. This is a profound point, and challenging to current professional concepts of clinical guidelines, evidence-based practice and care pathways. This will involve mental health services working in new ways, for example to avoid reinstitutionalization pressures (29) and reduce in-system stigma (30). Guides for mental health professionals are starting to become available (31) [downloadable for free from rethink.org/100ways].

RECOGNIZING A FOCUS ON PERSONAL RECOVERY

How can we recognize a recovery focus in mental health services, and how should the effectiveness of mental health services be evaluated?

Quality standards for a recovery-focussed mental health service are beginning to emerge. For example, the *Pillars of Recovery Service Audit Tool* (PoRSAT) identifies six pillars of service development: Leadership, Person centred and empowering care, Hope inspiring relationships, Access and inclusion, Education, and Research / Evaluation (32). The *Practice Guidelines for Recovery-Oriented Behavioral Health Care* cover eight domains: primacy of participation; promoting access and engagement; ensuring continuity of care; employing strengths-based assessment, offering individualized recovery planning; functioning as a recovery guide; community mapping, development and inclusion; and identifying and addressing barriers to recovery (33, 34). Finally, the *Recovery Promotion Fidelity Scale* assesses organization performance in six domains: Participation and acceptance; Self-determination and peer support; Collaboration; Quality improvement; Staff development; and Miscellaneous (35). At present, these standards are not widely used. Possible explanations might

include that a recovery orientation is viewed as an optional extra or a passing fad rather than a permanent and central activity, or that there is a general negative attitude towards any process measurement.

Despite these developments, there is as yet no consensus on an accreditation process to identify a recovery focus in services. This is unfortunate, because it allows any service to incorporate the term recovery into its name, irrespective of its actual approach. In the future it will be of benefit when an accreditation process emerges, although this will be challenging: needing to consider staff values, engagement with community services, process issues such as hope promotion, and so forth. Challenging but not impossible, as shown by the Fidelity Assessment Common Ingredients Tool (FACIT) measure of fidelity for consumer operated services, which assesses program structure, environment, belief systems, peer support, education and advocacy (36).

Given the centrality of relationships in supporting recovery (6), an alternative to assessing service-level characteristics is to focus on what happens in the consumer-clinician relationship. The Recovery-Promoting Relationships Scale is a 24-item consumer-rated measure about their experience of the relationship with their provider (37). It includes items such as *My provider helps me recognize my strengths*, *My provider helps me find meaning in living with a psychiatric condition*, *My provider encourages me to take chances and try things*, *My provider sees me as a person and not just a diagnosis*, and *My provider believes in me*. The unpublished Elements of a Recovery Facilitating System (ERFS) measure from the Yale Program for Recovery and Community Health assesses the extent to which the mental health system supports the individual in their recovery journey, and includes items such as *Staff seem to hold hope for me*, *I have a say on how programs are run*, and *Role models I can learn from work in the program*. Finally, the Sainsbury Centre for Mental Health in England published "10 Top Tips" that identify aspects for workers to reflect on following each interaction with service users, including items such as *Did I help the person identify and prioritize their personal goals for recovery – not professional goals?* and *Did I identify examples from my own "lived experience," or that of other service users, which inspires and validates their hopes?* (38).

In the absence of universal quality standards, it is helpful to identify domains which merit future consideration. We now consider two candidate domains: belief markers and discourse markers. For each domain, we propose some (un-evaluated) litmus tests which might indicate a focus on personal recovery.

BELIEF MARKERS

Some beliefs in traditional and personal recovery focussed services are compared in Table 1.

Table 1. *Beliefs in Two Types of Mental Health Service*

Beliefs in traditional mental health services	Beliefs in recovery-focussed mental health services
We already "do" recovery	Recovery is a journey not a destination, and we are on the way, but have a long way to go
Recovery begins with recognizing you have a mental illness	Recovery begins by reclaiming a sense of who you are
My job is to diagnose or formulate, then provide treatments or interventions for mental illness	My job is to support the person in their journey towards a more meaningful and enjoyable life
My primary approach to relating to consumers is as an expert	My primary approach to relating to consumers is as a coach or a mentor
I have a duty to intervene	I have some must-dos, but I employ several approaches to avoid my agendas dominating our work together
I decide when compulsory treatment is necessary	Approaches such as Advance Directives minimise the extent to which I decide when compulsion is necessary
Staff and consumers are fundamentally different – they have a mental illness, we do not	Staff and consumers are fundamentally similar – we are all trying to live a meaningful and enjoyable life
It is better not to be open if I have my own experience of mental health problems	Being open with other staff and clients about my own strengths and vulnerabilities is a positive asset

A recovery-focussed service has a balanced view about the impact of clinical practice. It recognizes that many consumers benefit from the traditional practices and values of mental health services. The problem is that not all consumers benefit, and some are harmed. So the orientation of the service is towards doing better over time. This creates a learning organization culture, in which performance information is highly valued, and the twin characteristics of ambition and modesty are present.

Other beliefs become evident in behavior. For example, if the consumer needs to "game" to get their needs met (e.g., becoming abstinent before getting housing, or reporting no voices before being discharged), this may be because of unstated clinical assumptions that treatment

Table 2. *Discourse Markers of a Recovery-Focussed Mental Health Services*

Clinical term	Problem	Potential alternative
Case management	People are more than a case (of schizophrenia, depression etc.)	Recovery support
Case presentation	This creates an expectation that what needs presenting, and therefore what matters, is the illness part	Recovery presentation
Has a diagnosis of…	When used without any qualification this becomes reified – seen as a true thing instead of a professional construction	Meets criteria for a diagnosis of…
Patient / consumer / peer, etc.	Puts the person and their experiences into a socially-defined category, instead of encouraging self-definition	Ask the person how they want to be referred to
Treatment-resistant	Locates the reason for not benefiting as in the person AND pejorative AND normally a misleading synonym for medication-resistant	Not benefiting from our work with him/her
The treatment aims are…	Treatment should be secondary to recovery goals, rather than an end in itself	The recovery processes being supported are…
Maintaining boundaries	Has implications of a fortress mentality, and needing to defend against harm from "the other"	Creating sustainable relationships
Introducing as "I am Dr. Smith"	Positions the professional as high social status and imposes a clinical frame of reference which constrains the resulting discourse	"Please call me Sam or Dr. Smith, as you prefer"
Maintenance, stabilization	Expecting no improvement is self-fulfilling AND pejorative	Consolidating gains
Risk management	Views all risks as to be avoided, so does not encourage personal growth	Harmful risk and positive risk-taking

needs to come before other types of help or support, or that illness-related needs should be met before meeting non-illness needs. The overarching behavioral marker is whether the person is treated as the professional would like to be treated. Housing provides an example. Some professionals would love to live with a group of other people from the same profession, and others would hate it. Few would be pleased if their request for housing was responded to with a requirement that they go on a course to learn to be a good tenant!

We turn now to the language of recovery.

DISCOURSE MARKERS

There is no right way of talking about recovery. Language is constantly evolving, so any linguistic symbol (i.e., a word or phrase) attracts unintended meanings over time. For example, in New Zealand the term "peer" is used for people who self-identify as having used mental health services, since the term "service user" is seen by some as having negative connotations of being a ravenous consumer of resources. Similarly the term resilience is preferred to recovery by younger people, because it has fewer associations with illness.

To some extent, therefore, the language used is irrelevant. What matters is the core values, rather than the words an individual professional uses (which are influenced by profession, education, context, etc.). However, since language shapes how we see and construct the world, it is important to consider how to language recovery, i.e., to use shorthands which foster rather than inhibit the recovery journey. Some general principles can be identified. For example, person-first language is helpful – talking about the person experiencing psychosis or the person with schizophrenia (or, even better, the person with a diagnosis of schizophrenia) rather than the schizophrenic or the schizophrenic patient serves to remind that diagnoses classify illnesses, not people (39). Similarly, the avoidance of illness-saturated linguistic environments – in which the only visible part of the person is the mental illness part – is important, so language to describe strengths and aspirations is a necessary counter-balance to discourse around deficits and disabilities. In Table 2 some traditional clinical terms and more recovery-promoting alternatives are put forward. Because there is no single best language, the intention is not to identify right and wrong ways of talking. Rather, the aim is to make visible some embedded assumptions and to suggest one of many approaches to languaging recovery.

Other discourse markers which are harder to specify in concrete terms are being open to discussion of power and choice (and its limits), and having a meaningful concept in regular use of expert-by-experience.

EVALUATING SUCCESS

Assessing the outcome of mental health service is vital, for both external and internal reasons. Externally, the

spending of tax-payer's money on mental health services rather than other demands can only be sustained long-term if there is evidence of value-for-money, and outcome evaluation provides the data about the benefits. Internally, a learning organization requires regular feedback on its performance. How can we evaluate the impact of a mental health service in ways which promote a focus on recovery? This challenge of acknowledging individual difference whilst using aggregated data is not new (40). The difficulty is summarized by Repper and Perkins: "*Traditional yardsticks of success – the alleviation of symptoms and discharge from services – are replaced by questions about whether people are able to do the things that give their lives meaning and purpose, irrespective of whether their problems continue and whether or not they continue to need help and support*" (41).

The challenge is to measure outcome in a way which is both aggregable and meaningful. Outcome data needs to be aggregated across individuals in order to meet many of the information needs of modern society – at the team, service, program, region and national planning levels. The problem from the consumer perspective with aggregation is loss of meaning (or granularity as epidemiologists would put it). Collecting information primarily for aggregation purposes leads to a focus on quantitative rather than qualitative data and on average rather than individual ratings. Both of these features are experienced by many consumers as unhelpfully reductionist and associated with loss of individual identity.

How can outcome be evaluated, whether in scientific investigation or routine clinical practice, in a way which is sensitive both to the idiosyncratic nature of recovery and the need to aggregate data? There are country-specific issues, and for example the challenges of assessing Psychiatric Rehabilitation Services in Israel have been outlined (42). But there are also general principles. Outcome evaluation should be based on a theoretical framework, and should measure what matters (43). One embedded issue is of course to whom the outcome matters, and a personal recovery orientation give primacy to outcomes which matter to the individual. The Personal Recovery Framework provides a defensible theoretical framework (6, 44). It identifies two classes of outcome which matter (i.e., promote personal recovery): valued social roles which reinforce social identity, and individual goals which contribute to personal identity. Both classes of outcome have features which are relevant for outcome assessment.

Valued social roles include employee, partner, family member, friend, citizen, free (i.e., non-detained) person, etc. Their value is relatively invariant – most (but of course not all) people want a job, a relationship, contact with their family, some close friends, the ability to exercise citizenship rights such as voting, not to be held in hospital or prison, etc. Assessment tends to be quantitative and dichotomous (or at least on an ordinal scale, such as unemployed – voluntary work – part-time work – full-time work), and hence easy to aggregate with little loss of meaning. They can be measured using objective quality of life indicators. For example, the MHA Village (mhala.org) uses ten observable outcome indicators, including *Live in the most independent, least restrictive housing feasible in the local community*, *Self-manage their illness and exert as much control as possible over both the day-to-day and long-term decisions which affect their lives*, and *Reduce or eliminate the distress caused by their symptoms of mental illness*.

The primary advantage of this kind of outcome is that they are based on normal social values, and so avoid illness-related lowering of expectations (either by staff in an effort to be realistic or by patients with internalized stigmatizing beliefs about what they can expect in life). Since most valued social roles occur outside the mental health system, they orientate the actions of the service towards increasing integration and participation by the person into their social environment, rather than encouraging a decontextualized and service-focussed view of the person. Their primary disadvantage is their invariance – some people get along very well in life without friends, or a partner, or a job. Attempting to impose normal social roles has the potential to be oppressive. However, assessing outcome is intrinsically value-based. It is less oppressive to be concordant with a value of personhood – the person with mental illness is before all else a person (45) – than with a value of clinical imperatives being more important.

Unlike valued social roles, individual goals differ from person to person. There is simply no way around this. Any evaluation of this aspect using predefined categories necessarily loses some of that uniqueness. No standardized measure will have items such as *Swim with dolphins*, *Breed snakes*, *Ride a motorbike*, or any of the other idiosyncratic goals individuals set and attain on their recovery journey (these are all real-life examples of recovery goals). Any attempt to squeeze personal identity into predefined boxes can be justifiably criticised for its loss of meaning. This does not of course mean that personal goals should not be included in outcome evaluation – they remain central, despite the difficulties in assessing

individual goal attainment. Rather, as Robert McNamara put it, "*The challenge is to make the important measurable, not the measurable important*" (46).

So an overall outcome evaluation strategy would measure two things. First, objective quality of life indicators, such as adequacy of housing, friendship, safety, employment and close relationships. Second, progress towards personal goals. This has relevance to both scientific research and routine practice.

RESEARCH AND CLINICAL IMPLICATIONS

This methodological proposal of focussing evaluation on social roles and personal goals can be applied in randomized controlled trials. For the invariant, predefined clinical end-point, more focus should be on valued social roles than traditional clinical preoccupations such as symptomatology and hospitalization rates. In addition, new technologies will be needed which allow for assessment of progress towards individualized goals. The most established approach is Goal Attainment Scaling, which involves the person identifying their own goals, along with markers of relative success or failure in attaining these goals (47). The resulting data can be aggregated across individuals to give an indicator of the overall success of the service at helping people to reach personally valued goals. But the approach is time-consuming and complex. Another approach is to identify a list of standardized outcome measures covering a range of domains, and for the consumer to identify the most relevant outcome measure from the list (48). This allows a degree of tailoring of outcome to each individual, without the complexity involved in Goal Attainment Scaling. Data can be easily aggregated, but using a predefined list of outcome measures reduces the extent to which assessment is individualized. Both of these approaches are currently being evaluated in the REFOCUS Study in England (researchintorecovery.com), which is maximizing the ecological validity of the randomized controlled trial by using personal goals (i.e., different for each participant) as the primary outcome.

In addition, this outcomes framework can be applied in routine clinical practice. The choice of outcome measure is based on an understanding of what is important, and an orientation around personal recovery challenges some traditional approaches to outcome measurement which focus on clinical imperatives, e.g., symptomatology, risk. Routine use of outcome measures is well-developed in some countries (49), and the most commonly mandated measure is the staff-rated Health of the Nation Outcome Scale (50). This approach gives primacy to the staff perspective, and does not reflect the areas of greatest importance to people using mental health services (51). An orientation towards personal recovery will require a different approach to routine outcome measurement, which actively aims to produce benefits at multiple levels in the system. At the person level, greater visibility of the individual's goals can inform clinical decision-making about the most appropriate intervention. At the local level, aggregated data can provide a more recovery-sensitive measure of casemix. This can be used for workforce planning, to better match the skill-mix in a team with the needs of people on the team caseload. At the country / regional level, using an explicitly recovery-oriented approach to routine outcome measurement is one approach to shifting the culture of care: talking about recovery is in itself an intervention. Mental health systems which can show they are increasing the attainment of valued social roles and increasing the proportion of personally valued goals being met are likely to be supporting recovery in their practices.

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