

Uses and abuses of recovery: implementing recovery-oriented practices in mental health systems

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An understanding of recovery as a personal and subjective experience has emerged within mental health systems. This meaning of recovery now underpins mental health policy in many countries. Developing a focus on this type of recovery will involve transformation within mental health systems. Human systems do not easily transform. In this paper, we identify seven mis-uses ("abuses") of the concept of recovery: recovery is the latest model; recovery does not apply to "my" patients; services can make people recover through effective treatment; compulsory detention and treatment aid recovery; a recovery orientation means closing services; recovery is about making people independent and normal; and contributing to society happens only after the person is recovered. We then identify ten empirically-validated interventions which support recovery, by targeting key recovery processes of connectedness, hope, identity, meaning and empowerment (the CHIME framework). The ten interventions are peer support workers, advance directives, wellness recovery action planning, illness management and recovery, REFOCUS, strengths model, recovery colleges or recovery education programs, individual placement and support, supported housing, and mental health dialogues. Finally, three scientific challenges are identified: broadening cultural understandings of recovery, implementing organizational transformation, and promoting citizenship.

Key words: Recovery, mental health services, peer support workers, advance directives, wellness recovery action planning, individual placement and support, supported housing, mental health dialogues, organizational transformation, promoting citizenship

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Understanding recovery as a return to symptom-free normality has been challenged in mental health services. People personally affected by mental illness have become increasingly vocal in communicating what helps in moving beyond the role of "patient". Recovery has been defined as "a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles" and "a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness" (1). This definition underpins mental health policy in the Anglophone world (2-6) and elsewhere (7).

At its heart, personal recovery is a subjective experience (8). There may be overlap between individuals, but there will be many subjective definitions of recovery, not least because the individual's understanding of his/her own recovery may change over time. Despite the policy consensus, it has proved challenging to develop a recovery orientation in mental health services which gives primacy to the individual's understanding. Indeed, some commentators suggest the concept has been "hijacked" (9) by professionals.

This paper sets out some recovery mis-uses ("abuses") and empirically supported pro-recovery approaches ("uses"). The authors comprise international experts from seven countries, and span lived experience (i.e. personal experience of mental ill-health), researcher, policy-maker and clinical perspectives.

We identify seven abuses of the concept of "recovery".

ABUSE 1. RECOVERY IS THE LATEST MODEL

With the spreading of the international movement towards recovery-oriented mental health services, organizations are increasingly trying to implement recovery-oriented practices.

Some organizations hire peers as a concrete manifestation of a recovery orientation. For example, thirteen states in the USA have committed to hire peers, and organizations in those states are now able to receive reimbursement for peer support services through a national insurance plan (10).

While consistent with recovery practice values (11), simply adding peers to the workforce of a mental health organization does not, by itself, create the paradigm shift needed. Indeed, a lack of organizational commitment can undermine the effectiveness of peer workers, if workers are disrespected or marginalized, or if roles are entirely assimilated into generic or clinical case work (12).

Implementing recovery-oriented practice should be person-centred and focus on helping individuals live a meaningful life (13), in contrast to setting clinical goals that are largely dictated by professionals (14). Shifting to practice that is built on equal partnership, hope-promoting and facilitating self-determination requires a transformation of services, practices and the paradigm within which they are delivered.

ABUSE 2. RECOVERY DOES NOT APPLY TO “MY” PATIENTS

The development of recovery ideology and practice has – like psychiatry – had a centre of gravity within psychosis. Some clinicians suggest that recovery as an approach is not relevant to the people they work with, because either the individuals are “too ill” or they do not have a psychosis diagnosis.

Neither stance is empirically defensible. Many pro-recovery interventions described in this paper are directly applicable to, and have been evaluated with, people in acute crisis. Similarly, empirical investigation of recovery has begun in many non-psychosis clinical populations (e.g., borderline personality disorder (15), forensic (16), eating disorders (17)) and various demographic groups (e.g., children (18), older adults (19), ethnic minorities (20)). Although the evidence base is less developed than in relation to psychosis, it is clear that recovery is at the least relevant to a wide range of clinical populations.

ABUSE 3. SERVICES CAN MAKE PEOPLE RECOVER THROUGH EFFECTIVE TREATMENT

Mental health professionals are often more accustomed to the clinical meaning of recovery than to personal recovery as it is understood by the recovery movement in mental health (1).

In clinical recovery, professionals diagnose and treat with the aim of curing people or reducing their symptoms. A review of all epidemiological studies with greater than 20-year follow-up showed that the majority of people with a diagnosis of schizophrenia attain clinical recovery (21), although the variance in this prevalence rate which is attributable to effective treatments is unknown. In personal recovery, the person leads his/her own journey towards a meaningful life and valued roles (22).

These two versions of recovery may be intertwined, but a person can experience one without the other. Traditionally, mental health services have been based upon either a clinical version of recovery or – at worst – a belief that recovery of any sort is not possible for many people. Mental health policy in many countries now requires services to build upon the personal version of recovery, and to give credence to the knowledge derived from lived experience of mental distress and recovery (23).

To support personal recovery, mental health systems will need to shift away from a dominance of institutional responses, drug treatments and coercive interventions. The focus needs to be on fostering hope and a belief in people, supporting self-determination, ensuring access to a broad range of community oriented services (including housing, education, employment, peer support, recovery education, crisis support, support in everyday living, drug treatments, talking therapies and advocacy), and promoting social

inclusion and human rights (24). Treatment may help personal recovery, but it can also hinder it, especially if it is the dominant response and is associated with coercive practices.

ABUSE 4. COMPULSORY DETENTION AND TREATMENT AID RECOVERY

Compulsory treatment is promoted as an effective way to “take care” of individuals when they cannot take care of themselves. For example, in England, the introduction in 2008 of community treatment orders (CTOs) was intended to reduce the number of individuals compulsorily detained in hospital. Despite 4,220 CTOs being made in 2011/12, the rates of compulsory admission have actually increased (from 44,093 in 2007/08 to 48,631 in 2011/12) (25).

A systematic review of the literature on compulsory treatment orders found little evidence of effectiveness in terms of health service use, social functioning, mental state, quality of life or satisfaction with care (26). In addition, the review found that it would take 85 outpatient commitment orders to prevent one readmission, 27 to prevent one episode of homelessness and 238 to prevent one arrest.

Compulsory treatment appears to be a broadly used intervention which recent evidence suggests is ineffective at reducing readmission (27). In addition, it works against the recovery goal of reclaiming a meaningful life – a process that is based on self-determination and respect for the individual as a citizen of society. Indeed, a study of 136 acute inpatient mental health units in England found that a focus on control (reduced access to medical staff, more use of security guards, poor ward structure) was associated with increased use of manual restraint and shows of force by staff (28).

Many countries now fund initiatives to reduce the use of compulsion (29). For example, Norway has since 2006 had a national action plan to reduce coercion (30).

ABUSE 5. A RECOVERY ORIENTATION MEANS CLOSING SERVICES

A recovery orientation is not a valid justification for service cuts.

It is reasonable to assume that a meaningful life is not lived within the boundaries of mental health services, and increased contact with non-mental health agencies and natural forms of support are often seen by service users as more valuable than contact with formal services (31). Therefore, a gradual reduction in contact with formal mental health services, as part of a jointly agreed plan and with support to access natural community supports (friendships, peer contacts, community groups, employment, etc.), is likely to be helpful in supporting someone’s recovery.

However, recovery is non-linear (32), and services have to be available to re-engage with people when needed.

Ineffective services should of course be replaced, but as an issue related to the improvement of mental health service delivery, not a matter of implementing recovery-oriented services. Reductions in services cannot be justified on the basis of meeting the goal of being supportive of recovery.

ABUSE 6. RECOVERY IS ABOUT MAKING PEOPLE INDEPENDENT AND NORMAL

The clinical framework underpinning most mental health services locates problems of exclusion largely within the individual. Clinical endeavours, therefore, focus on changing people through treatment (therapy, skills training, etc.), so that they “fit in”, i.e., become “normal” and “independent” of support and services.

But recovery is not about “getting better” or ceasing to need support – it is about “recovering a life”, the right to participate in all facets of civic and economic life as an equal citizen (33). This requires a framework predicated on a human rights and a social model of exclusion: “It is society that disables people. It is attitudes, actions, assumptions – social, cultural and physical structures which disable by erecting barriers and imposing restrictions and options” (34).

Inclusion and citizenship are not about “becoming normal”, but creating inclusive communities that can accommodate all of us. Not about “becoming independent”, but having the right to support and adjustments (in line with choices and aspirations) to ensure full and equal participation and citizenship (35).

The human rights of “persons with disabilities” – including those with mental health conditions – are outlined in the United Nations Convention on the Rights of Persons with Disabilities (36). These include the “right to live independently and to be included in the community” (Article 19). A right is not contingent on “getting better” or living without support, and explicitly includes the right to access the “assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation”.

Participation and inclusion do not involve changing people to fit in, but changing the world: “Having a psychiatric disability is, for many of us, simply a given. The real problems exist in the form of barriers in the environment that prevent us from living, working and learning in environments of our choice. . . [The task is] to confront, challenge and change those barriers. . . that impede and thwart our efforts to live independently and gain control over our lives and the resources that affect our lives” (37).

ABUSE 7. CONTRIBUTING TO SOCIETY HAPPENS ONLY AFTER THE PERSON IS RECOVERED

Work, whether it is paid, voluntary or household work, is the major way most people make a contribution to society. Work supports recovery (38). Most people who use mental

health services are capable of working most of the time, yet 70-80% of people who use mental health services in most Western countries are unemployed, a higher proportion than any other disability group (39,40).

Self-stigma, anticipated discrimination and discrimination in services and society contribute to these high unemployment rates (41-43), as can deficit-based services with low employment expectations for people with major mental distress, and employers who lack knowledge of good employment practices for this group of people (44).

Currently, governments in many Western countries are attempting to reduce the numbers of people receiving welfare benefits or pensions, often with a punitive rather than incentive-based approach. Advocates who lobby against this approach to welfare have inadvertently created a discourse that focuses on the right to welfare over the right to work for people with mental distress.

Punitive welfare reform is not the fundamental injustice; it is the number of people who are out of work. The whole community benefits when it is assumed that people with mental health problems can work, when they have the same rights as others to determine their contribution, and when they have reliable access to welfare if or when they cannot work.

MAXIMIZING SUPPORT FOR RECOVERY

Is recovery just new wine in old bottles (45)? In other words, does supporting recovery mean more than just optimal implementation of what we already know is best practice? Certainly it is reasonable to assume that consistent implementation of best practice is better than inconsistent implementation, with some estimates that optimal treatment and coverage would avert 28% of burden (compared with 13% burden averted at present) (46). However, a systematic review has identified five key recovery processes as connectedness, hope and optimism, identity, meaning and purpose, and empowerment (the CHIME framework) (32). These recovery processes differ from traditional clinical outcome targets, and interventions targeted at these processes are needed.

We now describe ten empirically supported pro-recovery interventions. Inclusion criteria were interventions that target recovery outcomes such as the CHIME framework, and have emerging or established supportive empirical evidence based on experimental investigation. They are intended as illustrative exemplars rather than a prescriptive list of interventions. The aim is to identify the types of intervention which could be expected to be provided in a recovery-oriented mental health system.

Peer support workers

Peer support emerged from the user/survivor movement, and originally developed outside the mainstream mental

health system. It is based on recovery values of hope, self-determination over one's life, participation in the service, mutuality, and the use of lived experience knowledge to help each other.

Informal peer support comes from natural supports such as family and friends. By contrast, formal peer support involves workers who are either employed in autonomous peer-run services outside traditional mental health services, or partner with professionals within a traditional mental health or social service.

Peer support workers are individuals with mental illness who identify themselves as such, and who use their lived experience to support others to recover. Key features of their role are clear (47), and implementation guidelines are now available (48).

A substantial and positive evidence base now exists for peer support services (47), identifying the experience and benefits of being a peer support worker (49-51), changes in workplace structure made to sustain the delivery of peer support services (52-54), and description of changes initiated by peer support workers (55,56).

Evidence from seven randomized controlled trials (RCTs) evaluating the impact of peer support workers found consistent benefits in relation to clinical outcomes (engagement, symptomatology, functioning, admission rates), subjective outcomes (hope, control, agency, empowerment) and social outcomes (friendships, community connection) (57). RCTs on peer-led self-management interventions in the Netherlands (58) and USA (59,60) showed benefits in relation to having a recovery role model, pursuing recovery, hopefulness, self-perceived recovery, symptom scores and quality of life. A Cochrane review identified eleven randomized trials involving 2,796 people in three countries (Australia, UK, USA), showing equivalent outcomes from peer support workers compared with professionals employed in similar roles (61).

Advance directives

People with mental illness are almost by definition vulnerable to experiencing emotional crisis. Recent healthcare technologies support people to remain in control during crisis. For example, an advance directive involves specifying actions to be taken for the person's health if capacity is lost in the future. Actions may involve treatment or specify a proxy decision-maker.

Advance directives have strong empirical support (62). A variant increasingly used in a mental health context is joint crisis plans, which are developed in collaboration with the clinical team. RCT evidence about joint crisis plans in psychosis shows benefits for reduced compulsory treatment (63), service use (64) and increased control (65). Trials in other clinical populations are underway (66).

Wellness recovery action planning

Self-management of symptoms is a major trend across all chronic disease groups. The wellness recovery action planning (WRAP) tools and processes support self-management with a specific focus on recovery-oriented mental health services.

WRAP is used to create recovery plans, by guiding individuals and groups of people to reflect on what has assisted them to stay well in the past, and to consider strategies that assisted others with their recovery (67). Planning tools in the "wellness toolbox" focus on self-management, from identifying fundamental strategies that enhance daily well being, to recognizing and dealing with triggers to distress through crisis planning.

The focus is on approach motivation (defining wellness and supporting goal striving) rather than avoidance motivation (e.g., symptomatic relief), in line with the insight from positive psychology that positive ("approach") goals are more likely to be sustainably attained than negative ("avoidance") goals (68). The process relies on peer facilitation, to activate the hope-inducing benefits of authentic role models (69).

RCT evaluation of outcomes for participants (n=519) at eight outpatient community mental health centres in an eight-week peer led intervention, compared with usual care and wait-list for WRAP, showed benefits in symptom profile, hope and quality of life (60).

Illness management and recovery

The illness management and recovery program (IMR) is an empirically-supported standardized intervention to teach illness self-management strategies to people with a severe mental illness (70).

It can be provided in individual or group format, takes five to ten months to complete, and comprises five empirically based strategies: psychoeducation to improve understanding about mental illness and treatment; cognitive-behavioural approaches to improve medication adherence; training in the prevention of relapses; social skills training to buffer stress and strengthen social support; and teaching coping skills to reduce the distress and severity of symptoms.

The centrality of medication adherence and psychoeducation about mental illness in IMR can present a barrier to its use by people seeking to support recovery. Supporting recovery is not incompatible with diagnosis and medication, but a barrier arises when diagnosis and medication are assumed to come first in steps towards recovery (71) (see Abuse 3). However, IMR begins with and focuses on self-directed problem definition, problem solving and pursuit of personally meaningful goals, all vital elements of recovery support (72,73).

RCT evaluations indicate IMR can significantly improve symptomatology, functioning, knowledge and progress towards

goals for people in supportive housing (74), outpatient services (75), and community rehabilitation centres (76).

REFOCUS

The REFOCUS intervention increases the recovery orientation of community adult mental health teams.

The manualized intervention (77) is theoretically based (32,78). Staff are trained and supported through reflection sessions and supervision to use three working practices. First, to maximize person-centred care planning, staff discuss the values and treatment preferences of the service user, using conversational, narrative and visual approaches. Second, staff use a standardized assessment (79) to identify the service user's strengths, so that care planning will be focused on amplifying strengths and ability to access community supports, as well as on deficit amelioration. Third, staff support active goal-striving by the service user towards his/her personally valued goals. Additionally, the staff-service user relationship is targeted by training staff to use coaching skills.

The REFOCUS intervention is being evaluated in a multi-site cluster RCT (80), which is using innovative approaches to assessing recovery support (81) and hope (82).

Strengths model

The strengths model of case management aims to help people with mental health problems to attain goals they set themselves by identifying, securing, and sustaining the range of environmental and personal resources that are needed to live, play, and work in a normally interdependent way in the community (83).

It has been used broadly and over decades in social care sectors in the USA, and in clinical services in Japan, Hong Kong and Australia (84). The evidence base comprises four RCTs (85-88) and several pre-post evaluations (89), showing improved psychosocial outcomes (especially for symptomatology and social functioning) and consumer satisfaction (84). Greater fidelity is associated with more improved consumer outcomes (90).

Recovery colleges or recovery education programs

People with psychiatric disabilities have emphasized the importance of education as a tool to assist them in gaining the competencies needed to assume full citizenship (91).

Recovery colleges or recovery education programs are an educational approach to supporting the recovery and reintegration of people with psychiatric disabilities. This model of service provision was pioneered at Boston University in 1984 (92), and is now being introduced in Italy, Ireland and England (93).

There is robust supporting evidence for several key features (94), including co-production (95) and supporting self-management through education (96). College-specific evaluation evidence is positive but limited (97).

Individual placement and support

People who cannot work should have easy access to welfare, and positive incentives to return to work. But most people with mental health problems want to work (98), though they need support in choosing, finding and keeping work (99).

Individual placement and support is an intervention which provides this support (100), and has a strong evidence base (101). A Cochrane review synthesized 18 RCTs of reasonable quality, and showed 18-month employment rates of 34% for recipients of the intervention, compared with 12% for pre-vocational training (102). For example, a six-country European RCT showed that individual placement and support was superior to the local alternative in each site, in terms of helping people find and maintain paid employment (103).

Follow-up studies conducted after 8-12 years confirm that the greater effectiveness of this intervention is sustained over the longer term (104,105), and there is evidence of cost savings through reduced mental health service use and lower reliance on welfare benefits (106,107).

Supported housing

Research suggests that around 30-40% of the urban homeless population live with a severe mental illness. Safe and secure permanent housing can act as a base from which people with a severe mental illness can achieve numerous recovery goals and improve quality of life (108,109). The housing first intervention involves rapid re-housing in independent accommodation. This approach has an emerging evidence base showing improved outcomes (110) and reduced costs (111).

People with a severe mental illness should have access to a range of housing options, with the capability to exercise choice regarding preferences.

Mental health dialogues

The active involvement of mental health service users, relatives and friends is essential for the development of recovery-oriented mental health practice and research (112). However, the idea that mental health is everyone's business, regardless of their background and experience, and accepting each other as equally entitled experts, remains a challenge. Dialogue groups (also known as psychosis seminars) are an approach to addressing this challenge.

A mental health dialogue meeting is a community forum where service users, carers, friends, mental health workers, and others with an interest in mental health participate in an open dialogue. Meetings address different topics, e.g. a task force on stigma-busting, or a work group on trauma and psychosis. In German-speaking countries, well over one hundred dialogue groups are regularly attended by 5,000 people (113), and international interest and experiences are growing (114).

Dialogues facilitate a discrete and independent form of acquisition and production of knowledge, and drive recovery-oriented changes in communication and structures.

REMAINING SCIENTIFIC CHALLENGES

Although the CHIME framework has been shown to apply across those cultures which produced guidelines included in the review (115), the generalizability of the concept of recovery remains a concern. Specifically, assumptions embedded in recovery may be “monocultural”, and broader concepts of community and cultural resilience and well-being may be needed. For example, an important issue is the collectivist versus individualist value paradigm (116). In collectivist cultures, such as Maori (the indigenous people of New Zealand) and Chinese ones, emphasis is placed on interdependence among family members and relatives over and above the independence that is often promoted in Western cultures (117). Apart from culture, the mental health system and service context (118) are also important considerations. For example, middle- and low-income countries may not have the infrastructure, such as budget and community-based services, to support basic mental health care (119), let alone recovery approaches.

It is important to investigate how the concept of recovery is interpreted by service users and health professionals within a non-Western cultural context (120-123). Can recovery-related assessment and fidelity scales be applied with reliability and validity (124)? By investigating factors that facilitate or hinder recovery for individuals from diverse backgrounds, more culturally applicable recovery concepts can be developed which will better address service users’ needs and rights.

An understanding of how to transform services is emerging. A synthesis of international guidance on supporting recovery identifies four levels of practice: supporting personally defined recovery (what interventions are offered), working relationship (how interventions are offered), organizational commitment (what is the “core business” of the mental health system?), and promoting citizenship (supporting the experience of wider entitlements of citizenship) (78). Most interventions reviewed in this paper address the first two of these levels. The Implementing Recovery – Organizational Change (ImROC) initiative across England addresses the culture of mental health services (93), using a learning set approach to helping organizations address ten key organizational challenges (125).

The final frontier is perhaps reducing and removing the barriers which prevent individuals experiencing full entitlements of citizenship (126). For mental health systems, this will involve transformation away from a “treat-and-recover” world view, in which priority is given to the provision of treatments with the aim that the person will then become ready to re-engage with his/her life. Empirical investigations of the concepts of “work-readiness” (in individual placement and support) and “housing-readiness” (in housing first) have found them to be inadvertently toxic concepts, which reduce hope and limit expectations. It has been argued that this change of emphasis applies more widely than just support for employment and housing (127).

However, the broadest – and most important – challenge is societal change, which will involve professionals and people with lived experience becoming partners (112) and social activists (128), to challenge stigmatizing assumptions that people with mental illness cannot, or should not, have the same citizenship entitlements as anyone else in their community.

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