RECOVERY – RESHAPING OUR CLINICAL AND SCIENTIFIC RESPONSIBILITIES

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SUMMARY

Context: Advocacy for Recovery has been joined by research offering new perspectives on mental health policy, treatment, rehabilitation and anti-discrimination efforts.

Objectives: Chances and challenges of a Recovery model for the mental health field will be presented and discussed.

Key messages: Recovery is currently widely endorsed as a guiding principle of mental health policy. New rules for services, e.g. user involvement and person-centred care, as well as new tools for clinical collaborations, e.g. shared decision making and psychiatric advance directives, are being complemented by new proposals regarding more ethically consistent anti-discrimination and involuntary treatment legislation as well as participatory approaches to evidence-based medicine and policy.

Recovery advocacy has been joined by research on recovery and resilience resulting in new data on the long-term perspectives of people experiencing common as well as severe mental health problems. Definitions of remission and recovery as well as the concept of chronicity are under debate. Research questions regarding recovery as a process as well as an outcome warrant scientific efforts enabling the integration of different perspectives as well as different methodologies.

Conclusions: Consequences and challenges of the Recovery model need to be tackled from different perspectives by clinicians, researchers, policy makers and – essentially - users and carers and their representatives in order to be fully explored and brought to life.

Key words: recovery – evidence base – user involvement - trialogue

INTRODUCTION

During the last years important English-speaking countries like USA, UK, Ireland, Australia, New Zealand, and Canada have embraced recovery-orientation as a guiding principle of their mental health policy. Major stakeholders and different professional groups have expressed their loyalty to the concept. The implications of recovery orientation for our scientific responsibilities include the development of novel research policies and methodologies for many urgent research questions. Consequences for mental health policy, service provision and therapeutic relationships include new strategies and tools as well as evaluative data and attempts at system transformation. The collaboration between mental health professionals and users and former users of services is a key condition for the implementation of recovery. Guidelines, training modules and system transformation initiatives have been emerging alongside new experiences and research data as well as complex and controvers discussions.

CONCEPT AND DEFINITION

The idea of two meanings of recovery is a recurring one and not seldom corresponds to a focus on internal and external factors. Another classical discussion concerns ‘clinical’ and ‘social recovery’ with the traditional clinical outcome definitions like symptom reduction and functioning and quality of life corresponding to the former and economic and social independence to the latter. ‘Recovering from’ an illness in the clinical sense is defined as an outcome and thus differently from the process of being ‘in recovery’ (Davidson & Roe 2007), usually defined around self-determination and a life in the community despite symptoms or illness or disability. Bellack’s suggestion of ‘scientific’ versus consumer models (Silverstein & Bellack 2008) deals with the measurability of recovery as an outcome - usually in the form of symptoms, severity and functioning scales versus an ongoing process of overcoming adversity and striving towards what is important in an individual’s life, a notion that has also been defined as ‘personal recovery’ (Slade et al. 2008). The distinction between outcome and process is often viewed as critical (Meehan et al. 2008) and sparks the essential discussion on how to develop new assessments and methodologies in order to measure outcome in a valid form in a recovery-oriented clinical and scientific context (Slade & Hayward 2007).

Onken et al’s (2007) discussion concerns the divide between ‘those who believe recovery is the absence of symptoms’ and those ‘who view recovery as a positive sense of self achieved in spite of continuing symptoms or in recognition of one’s surmounting the social impact of illness’. Consequently, they focus on the importance of symptom self-management without necessarily ‘calling for the absence of symptoms’. This is probably one of the most important points in discussing about possibly fundamental differences between clinical and personal recovery, clinical and social or clinical and rehabilitative models as well as service-based and user-based recovery and might actually be key to the question whether and how best to communicate between the two different meanings.
REMISSION AND RECOVERY

According to the type of illness, remission can mean that no further symptoms of the illness are detectable or that symptoms are so minimal that they do not lead to any significant impairment in day to day life. For depression, anxiety, and bipolar disorder, such criteria for remission have already existed for many years, and various interventions, especially psychopharmacologic ones, can be assessed accordingly. In 2005, leading US schizophrenia-researchers have come together in a working group on “Remission in Schizophrenia” (Andreasen et al. 2005). As a reason for this new initiative, the authors cite the increasing interest among patients, families and advocates, but also professional experts, in the subject of recovery. In their introduction the authors argue that a great variety of criteria had been used previously; that new therapies in the psychosocial and pharmacological realms had been established; and that there was scientific evidence for the fact that negative prognostic estimations for the course of schizophrenia have been overstated. The European answer to this proposal expresses support for the aims of the US working group (van Os et al. 2006) to define clear-cut criteria for the assessment of course and outcome so that they can be assessed and compared. The Europeans are similarly indignant about the widespread ignorance and misjudgments concerning the course and outcome of schizophrenia. And they concur with the effort by the highest caliber researchers to clarify that remission of symptoms in schizophrenia has to be an important goal and should serve as a marker for treatment success.

Van Os et al. (2006) point out that the definition of remission by the exclusive use of symptoms has nothing in common with recovery. They see the abatement of symptoms as a necessary step in the direction of recovery. However, in both papers, recovery is defined as considerably more than this. Functioning in social roles, work, social relations, and quality of life are mentioned as important criteria, albeit still pose a challenge to measurement. The European authors define recovery as “moving forward” and “rebuilding lives”. They express the hope that operational criteria for recovery would become available in the future, and that there was scientific evidence for the fact that negative prognostic estimations for the course of schizophrenia have been overstated. The European answer to this proposal expresses support for the aims of the US working group (van Os et al. 2006) to define clear-cut criteria for the assessment of course and outcome so that they can be assessed and compared. The Europeans are similarly indignant about the widespread ignorance and misjudgments concerning the course and outcome of schizophrenia. And they concur with the effort by the highest caliber researchers to clarify that remission of symptoms in schizophrenia has to be an important goal and should serve as a marker for treatment success.

RESEARCH

Mike Slade’s example of a necessary debate regarding an intervention, which is known to reduce symptoms, but also fosters dependency and loss of hope gives an indication what kind of research is necessary if recovery outcomes are to be captured in a valid way (‘research is better than rhetoric’, Slade & Hayward 2007). He calls for the identification of the ‘active ingredients’ in recovery-focused mental health services, a work that would include finding out not only ‘what they do’ but also ‘how’ they do it. Fidelity Scales then would allow evaluation of just how successful services have been in promoting recovery. Regarding outcome measures that can capture recovery he draws our attention to the facts that they would need to reflect personal preferences and that research design must make the best use of both quantitative and qualitative approaches as well as user-led approaches. Liberman and Kopelowicz (2005) in a clear demand for a research concept for recovery from schizophrenia and operational criteria for both the process of ‘recovering’ and ‘recovery’ as an outcome argue for viewing process and outcome ‘in apposition, not opposition’. Julie Repper and Rachel Perkins (2003) clearly state the obvious: “Any services, or treatments, or interventions, or supports must be judged in these terms – how much do they allow us to lead the lives we wish to lead?” and John Strauss’ (2008) admonition regarding the question ‘whether a field that systematically ignores a considerable amount of data can be considered an adequate science’ is trying to encourage us for meeting the methodological challenges of research and theory of subjectivity. Of course, any relevant evidence-base in times of recovery-orientation would need to live up to be multiperspective and scientifically excel in multiple and mixed methods designs (Rose et al. 2006; Wallcraft et al. 2009).

In their 2003 article, Bill Anthony from Boston University and his colleagues Marianne Farkas and E. Sally Rogers outlined the requirements for scientific studies that aim to promote evidence-based supports in the age of recovery (Anthony et al. 2003). In addition to the important struggle to ensure that all interventions which are already backed by scientific evidence should be available to anyone who might benefit, future studies should be designed so that they can be measured against recovery-goals. In the following we present their expectations, which are topical and applicable to the international field:

Outcomes Emphasized in Evidence-Based Practice Research Should Include Those that Focus on Recovery and that Consumers Believe Are Most Critical

Most studies assess interventions according to the number of hospital days they are able to reduce. They deal with symptoms, readmissions, length and cost of inpatient stays and possibly also whether somebody has
been able to get a job. These types of outcome variables may not have much to do with the things that are important to people in achieving their goals and experience success. A voluntary hospital admission may be less relevant to people in recovery than the way they spend the majority of their days or where and how they live, and whether a person is meaningfully engaged and has friends. On the other hand, a distinction between voluntary and involuntary hospitalizations may be crucial, but is hardly ever mentioned in outcome studies. Obviously, the traditional criteria are inadequate. Success in social roles, like as an intimate partner, family member, among friends, in training or at work, or factors such as self-determination and self-efficacy, wellbeing, lessening of discrimination and curtailment of harmful treatment effects are variables that must gain prominence.

**Subjective Outcomes and Qualitative Approaches Should Assume Greater Credibility and Utilization within the Context of EBP Research**

Since recovery paths can take rather divergent individual courses, any research that is based exclusively on groups of subjects and on statistical relationships can only be of limited value. Such studies must be buttressed by scientific methods that can take individual experiences of persons into account and reveal certain unfolding processes. Quantitative procedures can only be utilized sensibly once qualitative methods have shed light on the way complex interventions make their impact and how transformation occurs.

**Researchers Should Attempt to Determine Why Currently Published, Evidence-Based Practice Research Has Rarely Demonstrated a Positive Impact on Recovery Related Outcomes**

It is a well-known fact that interventions whose impact on symptoms and hospital days has been clearly proven, may not have a scientifically measurable impact on recovery rates. This needs to change urgently, and we must find out how this might be possible. To achieve this, interventions as well as scientific methods must be improved. We cannot rely exclusively on randomized clinical studies, since there are important scientific concerns that require the use of more complex research methods and designs.

**Evidence-Based Practice Research Should Include More Studies of the Helper-Consumer Relationship, Which Appears to Be an Important Component of Recovery**

Some psychosocial programs have already shown that certain of their components are more effective than others. Nevertheless, these programs are still being offered and evaluated in their entirety. The scientific work of „breaking down“ programs into their components and identifying their effective elements, as well as the search for superior combinations of elements is essential for broadening the evidence base.

**Evidence-Based Practice Research Should Attempt to Unbundle the Program Models to Research Specific Practices Rather than Programs in General**

It has also been shown that many evidence-based programs are only effective locally, but cannot be replicated with equal success in other cultures or environments, i.e. urban vs. rural settings. Frequently, studies do not reveal under which circumstances interventions designed and for which subgroups of clients they are deemed to be appropriate. Much more work needs to be done in this area for the sake of promoting evidence-based services.

**Evidence-Based Practice Research Should Test Its Models for Applicability in Various Cultural and Contextual Conditions**

Apparently, the effectiveness of services is not merely dependent on its specific elements or its ways of organization. Their values and the image of humanity that undergirds them must play equally important parts. To examine these values and their effects systematically is another task of scientific research.

In sum this means that specific approaches and experimental methods are necessary to ensure that psychiatric services which want to measure up to recovery parameters can satisfy the criteria of evidence-based practice. Whenever it is feasible to undertake the necessary efforts and to optimize the scientific how, the concepts of evidence-based medicine and recovery can go hand in hand.

**RECOVERY-ORIENTED SERVICES**

While much of recovery is lived outside clinical settings there clearly are important responsibilities for clinicians in supporting and assisting persons with mental health problems in their efforts towards making full use of their health and resilience, and achieving their goals in life. For services and mental health workers recovery-orientation not only means to fight for a system that is able to offer all evidence-based interventions – currently only realized for a small proportion of people with severe mental illness. It also means to accept that what is essential for one person’s recovery is not necessarily what has been proven to work in a majority of a large group of patients.
Sometimes it is very specific and individual approaches that are most effective.

Patient self-determination, individual choice of flexible support and opportunities, interventions to promote empowerment and hope also in the long-term, as well as assistance in situations of calculated risk are new indicators of quality of services. In contrast to a deficit model of mental illness recovery orientation includes a focus on health promotion, individual strengths, and resilience. A shift from demoralizing prognostic scepticism towards a rational and optimistic attitude towards recovery, and broadening treatment goals beyond symptom reduction and stabilization need specific skills and new forms of co-operations between practitioners and service users, between mental health workers of different backgrounds, and between psychiatry and the public. New rules for services, e.g. user involvement and person-centred care, as well as new tools for clinical collaborations, e.g. shared decision making and psychiatric advance directives, are being complemented by new proposals regarding more ethically consistent anti-discrimination and involuntary treatment legislation as well as participatory approaches to policy decisions (Rose et al. 2006).

Simon Bradstreet summarizes the collected insights about recovery from the international literature in his survey article “Elements of Recovery: International Learning and the Scottish Context”, which can be accessed online (www.scottishrecovery.net). He understands recovery in the broadest sense of the term, offering a definition by William Anthony (1993) that outlines a satisfying, active and hopeful life even within the limitations of the illness. Developing a new sense and meaning of life is essential, while growing beyond the catastrophic outcomes of a psychiatric condition. Bradstreet summarizes the following shared elements of recovery from the international literature:

- **Hope:** Without hope recovery is not possible. There can be no change without the belief that a better life is both possible and attainable.
- **Meaning and purpose:** People find meaning in very different ways, e.g. some persons may find spirituality important while others may find meaning through the development of stronger interpersonal or community links.
- **Potential for change:** A recovery approach requires a fundamental belief that everyone has the potential for change. It challenges the traditionally pessimistic outlook of mental health professionals influenced by a historical belief in the chronic nature of some mental health problems. It also proposes that episodes of illness, while clearly distressing, can in fact be developmental and educative experiences.
- **Control:** It is central for recovery to have the subjective experience of having regained control over one’s life. People who use mental health services are sometimes denied an adequate level of involvement in their own care and treatment.
- **Active participation:** In contrast of being a passive recipient of services, recovery aims at active individuals who take personal responsibility of his or her care, often in collaboration with friends, family, supporters, and professionals.
- **Holistic and inclusive approach:** Recovery considers all elements of a person’s quality of life. It recognizes that the extent to which someone enjoys good health and well-being is influenced by a wide range of social, environmental and individual factors and is much more than the management of symptoms.
- **Environment:** External factors such as stigma and discrimination, employment and training opportunities, housing and social exclusion have a strong influence on recovery.
- **Optimistic and realistic approach:** Recovery is rarely a linear process, people will have periods where their recovery is slowed by a bout of illness.
- **Creative risk taking:** Services are rightly concerned about managing risk but the danger is that it becomes the overriding concern. For someone to overcome a disabling illness and become actively involved in their community requires an element of creative risk taking.

The approach of the Ohio Department of Mental Health (Townsend et al. 1999) as an example of a system-wide reorientation towards recovery has been met with great interest internationally and also informed the National Institute for Mental Health in England with their ‘Emerging Best Practices in Mental Health Recovery’ in 2004, which proposes several meanings of recovery. They include a restoration of health, experiencing a recovery-process, and the achievement of an acceptable quality of life and satisfaction in spite of persisting disabilities or an ongoing illness. They emphasize the significance of recovery as an individual process of combating the negative consequences of a mental illness or disorder, even if it may still persist. Recovery is whatever people experience when they become empowered to lead a meaningful life along with a positive feeling of belonging in their communities. This assessment has to come from the users themselves.

The phases of recovery begin with a state where a person lacks autonomy and needs help („dependent“), but is „unaware“ what exactly is going on. In this first, dependent/unaware, phase, it is frequently not apparent what the person’s problems and needs actually are, and there is no clear concept about what has to be accomplished, or no motivation to change anything. During this time there is a great demand for patience from the environment and the support systems. There is also a big challenge not to proceed in a resigned and devaluing manner, but rather to spend much time to convey information - often in many brief interactions - and to enhance awareness.

People who have learned to rely on the service system and have become somewhat familiar with their psychiatric conditions, but have not yet developed trust
in their own capacities, are entering the second phase »dependent/aware« where they live with an awareness of their dependency. This can be a result of institutionalization. The providers tend to take care of things for the users, rather than working in consort with them. Patients suffer from stigma and social exclusion. Self-worth and self-efficacy are minimal. Life is marked by unfulfilled dreams and desires.

During the third phase »independent/aware«, people are - once again - able to resume responsibility for themselves and their actions. They realize that they have to contribute to their own wellbeing and find ways to obtain support. Certain lifestyles are identified as risky and people pay more attention to their own health during this phase. At this time people also develop the capacity to tell their own story and show interest in helping others. Relationships are now increasingly based on mutuality. Some people assume tasks and leadership roles in advocacy and other social spheres. Relying on the mental health system becomes less and less important and looses its attraction. At this point the service system needs to encourage clients to become engaged in outside activities and support their independence.

The fourth phase »interdependent/aware« means to live one's life and to be in charge; finding supports whenever and in the way one needs them. Health-promoting interventions, such as psychotherapy and pharmacological aides, can continue without people staying involved in the mental health system. Their careers are elsewhere. If they do stay involved in the system, they serve in active roles, for example as paid co-workers or volunteers. Mental health providers can be supportive when clients are leaving the patient role behind. However, it must be clear that one can always come back in case of need during crises or for other kinds support.

Naturally, people are not neatly distributed into such cubbyholes, but it is helpful to think about which phase is currently relevant. It is also obvious that some people pass through some of these phases more than once.

The significance of each of the four phases for clients, clinicians and community support is being considered in great detail, dealing separately with each of the nine core-areas of service - clinical treatment, family support, self-help, work and meaningful activities, power and control, stigma, participation in community life, access to resources and training. This comprehensive matrix is the foundation of professional work. It provides a profile for demands and activities of providers. Staff qualifications, competencies, basic and continuing education as well as supervision are derived from it.

The definition of essential capabilities plays a core role in basic and continuing education and human resource development in all domains of health care and social services. They convey clearly which minimal requirements and basic competencies are expected from staff in recovery-oriented services. NIMHE's ten essential capabilities relate to the following domains:

- Working in partnership;
- Respecting diversity;
- Practising ethically;
- Challenging inequality;
- Promoting recovery;
- Identifying people's needs and strengths;
- Providing service user centred care;
- Making a difference;
- Promoting safety and positive risk taking;
- Personal development and learning.

Such orienting prescriptions are aimed at promoting a new culture in psychiatric services and therapeutic relationships. Both content and form of communication and organization need to express and promote the existence of hope. The values and aims of the individual, as well as their strengths must be at the center of all efforts. The right to full participation and self-determination, as well as protection from discrimination must move into the center of all efforts to promote recovery. All services need to aim towards a development beyond the limitations of the patient role and towards a self-determined, meaningful life.

COLLABORATION

Fred Frese, a psychologist and user activist with a diagnosis of schizophrenia, and his co-authors (Frese et al. 2001) have suggested that two different intentions must be considered in recovery-oriented services. On the one hand, relatives and mental health experts argue for interventions that are "evidence-based." They are especially keen in promoting such treatments for persons who are deemed incapable to speak for themselves and therefore most be especially protected from unproven or risky interventions. In the spirit of consumer-protection, such individuals must have access to services whose usefulness has been adequately proven and whose desired and untoward effects have been evaluated among large samples. These demands are far from being realized. We know that only a small fraction of persons with a severe psychiatric disorder are being treated in a manner that is comprehensive and commensurate with the current state of the art. For example, specific psychotherapeutic interventions, which exist by now for virtually all psychiatric conditions, are known to be effective. Nevertheless, they are not offered routinely. The same can be said for specific types of vocational rehabilitation and other support services. Such lack is obviously frustrating and gives cause for political advocacy, with the aim of making such knowledge widely available in practice. On the other hand there are many former patients who advocate for a recovery-approach that builds on subjectivity, autonomy and freedom of choice. Many people who have recovered from psychiatric conditions know that they were helped by things other than evidence-based services. Many times they benefited from individualized, unique, and idiosyncratic approaches. The only
proof of their effectiveness consists of the fact that they had indeed been essential in the recovery of certain individuals. Mental health experts often tend to discourage such inventive methods due to a lack of scientific data about their effectiveness. However, for consumers such personal support may be of the essence. Frese et al. (2001) make clear: Most service users need both: evidence-based interventions as well as individual, unusual solutions. Therefore: Let’s struggle together! Research must be done in both directions!

The current convergence of the interests and activities of service users and those of mental health professionals is a central element in coming to an understanding of these new developments. These would not have been possible other than as an extension and logical consequence of the achievements of the consumer movement. What is new in the role that recovery plays today is the increasing readiness and expertise of those users and mental health professionals who are engaged in collaborative efforts. The fact that empowered service users have had many successes and have been able to find ways of understanding about and influencing the professional mental health system, is key for any current developments towards recovery. Most conceptual and political considerations and decisions have evolved from collaborations between people with and without a lived experience of mental health problems and the psychiatric service system. Many of the most influential publications on this subject were written by users and ex-users of services and work-groups that have brought together individuals with and without personal experiences as psychiatric patients.

An innovative development, which has long been exclusive to the German-speaking countries, is called “Trialogue” (Amering et al. 2002) or “Psychosis Seminar” (Bock & Priebe 2005). In Trialog groups, users, carers and mental health workers meet regularly in an open discussion forum that is located on “neutral terrain” – outside any therapeutic, familial or institutional context – with the aim of communicating about and discussing the experiences and consequences of mental health problems and the psychiatric service system. Many of the most influential publications on this subject were written by users and ex-users of services and work-groups that have brought together individuals with and without personal experiences as psychiatric patients.


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REFERENCES


