Recovery and Severe Mental Illness: Description and Analysis

Robert E Drake, MD, PhD[1]; Rob Whitley, PhD[2]

[1] Professor of Psychiatry, Dartmouth Psychiatric Research Center, Lebanon, New Hampshire.
 Correspondence: Dartmouth Psychiatric Research Center, Rivermill Commercial Center, Suite B4–1, Lebanon, NH 03766; robert.e.drake@dartmouth.edu.

[2] Assistant Professor of Psychiatry, Douglas Mental Health University Institute, McGill University, Montreal, Quebec.

The notion of recovery has been embraced by key stakeholders across Canada and elsewhere. This has led to a proliferation of definitions, models, and research on recovery, making it vitally important to examine the data to disentangle the evidence from the rhetoric. In this paper, first we ask, what do people living with severe mental illness (SMI) say about recovery in autobiographical accounts? Second, what do they say about recovery in qualitative studies? Third, from what we have uncovered about recovery, can we learn anything from quantitative studies about proportions of people leading lives of recovery? Finally, can we identify interventions and approaches that may be consistent or inconsistent with the grounded notions of recovery unearthed in this paper? We found that people with mental illness frequently state that recovery is a journey, characterized by a growing sense of agency and autonomy, as well as greater participation in normative activities, such as employment, education, and community life. However, the evidence suggests that most people with SMI still live in a manner inconsistent with recovery; for example, their unemployment rate is over 80%, and they are disproportionately vulnerable to homelessness, stigma, and victimization. Research stemming from rehabilitation science suggests that recovery can be enhanced by various evidence-based services, such as supported employment, as well as by clinical approaches, such as shared decision making and peer support. But these are not routinely available. As such, significant systemic changes are necessary to truly create a recovery-oriented mental health system.

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Rétablissement et maladie mentale grave : description et analyse

La notion de rétablissement a été adoptée par les principaux intervenants au Canada et ailleurs, ce qui a entraîné une prolifération de définitions, de modèles, et de recherches sur le rétablissement. Il est donc de toute première importance d'examiner les données afin de démêler l'évidence de la rhétorique. Dans cet article, nous demandons d'abord aux gens vivant avec une maladie mentale grave (MMG) ce qu'ils disent du rétablissement dans des récits autobiographiques? Deuxièmement, que disent-ils du rétablissement dans les études qualitatives? Troisièmement, d'après ce que nous avons découvert sur le rétablissement, pouvons-nous apprendre quoi que ce soit des études quantitatives sur les proportions de personnes menant une vie de rétablissement? Enfin, pouvons-nous identifier des interventions et des approches qui peuvent consistentes ou non avec des notions de rétablissement fondées dont cet article ne fait pas état? Nous avons constaté que les personnes souffrant de maladie mentale déclarent fréquemment que le rétablissement est un cheminement, caractérisé par un sentiment grandissant de pouvoir et d'autonomie, ainsi qu'une participation accrue à des activités normatives, comme l'emploi, l'éducation, et la vie communautaire. Cependant, l'évidence suggère que la plupart des personnes souffrant d'une MMG vivent encore d'une manière qui ne concorde pas avec le rétablissement; par exemple, leur taux de chômage excède 80 %, elles sont vulnérables de façon disproportionnée à l'itinérance, aux stigmates, et à la victimisation. La recherche issue de la science de la réadaptation suggère que le rétablissement peut être amélioré par divers services fondés sur des données probantes, comme le soutien à l'emploi, et par des approches cliniques, comme la prise de décisions partagée et le soutien des pairs. Mais ces services ne sont pas régulièrement offerts. Ainsi, des changements systémiques importants sont nécessaires pour véritablement créer un système de santé mentale axé sur le rétablissement.

In times past, severe mental illnesses (SMIs), such as schizophrenia, were generally considered chronic and incapacitating diseases that worsened over the life course,[1] with most patients given a dire prognosis.[2,3] The mental health system reflected this nihilistic belief, with patients discouraged from engaging in normative activities, such as employment, education, childrearing, intimate relationships, and independent living.[4] Patients frequently developed service-dependent lifestyles, involving lengthy institutionalization, heavy medication, sheltered activities, and supervised housing.[5] Unlike other areas of medicine, psychiatry extended its authority to encompass most aspects of patients' lives, including where they lived, with whom they associated, and what they did with their time.[6]

This paternalistic perspective has recently been challenged through an international paradigm shift toward the notion of recovery.[7] Key stakeholders, including government commissions, health service managers, and clinical leaders, herald the new recovery approach. Academics and researchers have produced thousands of books and articles on the concept of recovery, with numerous competing definitions and models.[5,8–10] Likewise, many administrators, clinicians, and researchers readily use the rhetoric of recovery to further various projects or activities.[11,12] Many providers are triumphantly announcing that they offer recovery-oriented services, often without defining what that entails and without data to support the contention.[13] The result is a multitude of interventions, services, and approaches proudly (if not glibly) described as recovery-oriented.[14,15] One suspects these could be meaningless shibboleths—new labels for traditional approaches. Indeed, Ridgway[16] stated over 10 years ago that "there is a growing concern that recovery may become the latest catchphrase used merely to reframe traditional activities."[p 335] This concern applies as much now as it did then.

The rapid proliferation of definitions, models, and research on recovery makes it vitally important to examine the data to disentangle the evidence from the rhetoric. In this paper, instead of examining recovery from a top-down perspective, we build from the ground up. First, we ask, what do people living with SMI say about recovery in autobiographical accounts? Second, what do they say about recovery in qualitative studies? Third, from what we have uncovered about recovery, can we learn anything from quantitative studies about proportions of people leading lives of recovery? Finally, can we identify practices that may be consistent or inconsistent with the grounded notions of recovery unearthed in this paper?

Autobiographical Perspectives

Numerous people with SMI have written poignant personal memoirs regarding the lived experience of recovery. Seminal works include that of Patricia Deegan,[17,18] Elyn R Saks,[19] as well as Sherry Mead and Mary Ellen Copeland.[20] In their various writings, these authors give their own definitions and perspectives on recovery, as well as outlining barriers

Highlights

- People with SMI generally consider recovery a journey of small steps, characterized by a growing sense of agency. Participation in everyday activities, routines, and normative life processes, such as employment and education, are frequently considered as both facilitators and indicators of recovery. They also note the need for a humane and empowering mental health system that encourages choice and autonomy.

- Research from rehabilitation science indicates that there are many evidence-based interventions that can facilitate improvement on the recovery domains identified above. These include supported employment and supported housing approaches. Shared decision making in the clinical encounter is also an approach consistent with the desire of people with mental illness to have more choice and agency.

- However, the above practices and approaches that foster recovery are not routinely available. For recovery to become truly integrated into a mental health care system, widespread systemic change is necessary. This includes the implementation of services that promote financial, residential, and personal independence, as well as normative adult roles, such as employment and social connectedness.

and facilitators thereof. Several scholars have analyzed such first-person accounts to discern common themes across recovery narratives.[16,21,22]

A first theme emerging from these analyses is that recovery is routinely considered a process rather than an outcome—a deeply personal experience related to an individual's life aspirations. Saks[19] discovered that "I could be mentally ill and lead a rich and satisfying life."[p 333] The metaphor of recovery as a journey is common. Deegan[17] states that "recovery is a process, a way of life, an attitude . . . a series of small beginnings with very small steps . . . each person's journey of recovery is unique."[p 16] Ridgway[16] also notes the importance of "small concrete steps" similarly stating that "each person's journey of recovery is individual and unique."[p 339] Many examples of such small steps are given. Mead and Copeland[20] note that this can be as mundane as "buying ingredients for supper instead of a TV dinner."[p 321] Wurtzel[23] found that she was "amazed that I can even get out of bed"[p 2] during her worst bouts of depression. These steps gather length and pace as recovery progresses, with Wisdom et al[21] describing a "striving for normalcy . . . to achieve major developmental or life milestones such as having a career or raising children."[p 492]

A second theme arising from these sources is the importance of everyday activities, routines, and normative life processes in fostering recovery. Saks,[19] currently a university professor with lived experience of schizophrenia, notes that her

> very survival hinged on structure and predictability . . . work is my solace . . . when I am away from it I lose all my bearings . . . I need to be in my office seven days a week.[p 332]

Jamison[24] similarly noted the importance of the "kind of evenness and predictability most people had, and probably

took for granted, throughout their lives"[p 167] in her recovery from bipolar disorder. In similar language, Wurtzel[23] wrote that "I am happy to be doing anything routine and normal . . . all I want is that nice, even keel."[p 328] All of the above authors described the importance of education, as well as meaningful employment, in their recovery. All wryly note that they had frequently been advised to quit both employment and education, or at least downgrade their aspirations, by clinicians, colleagues, and friends.

Third, these autobiographical narratives commonly emphasize the need for a humane and empowering mental health system that encourages patient choice, agency, and autonomy. Deegan[18] notes that "we can speak for ourselves . . . we have a voice . . . we have the right to be heard . . . we can become self-determining."[p 92] She notes that such empowerment can come about through a mental health system that provides "choices, options, information, role models, opportunities for bettering one's life."[18, p 96] Mead and Copeland[20] make similar remarks, emphasizing the importance of "choice and personal responsibility"[p 324] regarding treatment decisions. They critique the "paternalistic . . . and one-sided and infantilizing"[20, p 317] relationships, which they felt characterized much clinical work, arguing instead for "hope, personal responsibility, education, advocacy and peer support."[p 315] Ridgway[16] also notes the importance of peers, stating that they "can spark and support recovery."[p 340] Saks[19] compared treatment in 2 different jurisdictions. In one, she notes that

> they never forced any of it [treatment] on me, and each time the decision was mine. Even at my craziest, I interpreted this as a demonstration of respect.[p 80]

In the other jurisdictions, coercion, restraint, and seclusion were frequently used against her will, which she considered brutal and degrading. This latter point is made by others who note "there is no place for harsh restraining devices, seclusion rooms and body searches."[20, p 327]

To conclude this section, many personal memoirs include vivid examples of humane clinicians who listen, care, and empower patients to make their own decisions. These clinicians are presented as unimpeachable paragons of good practice. Saks[19] notes "psychiatrists and therapists saved my life"[p 339] and Jamison[24] notes "the importance of small kindnesses."[p 151] Also, the topic of medication is frequently discussed, with Mead and Copeland[20] saying that "medications are one of many options and choices for reducing symptoms,"[p 323] though stating categorically that medication decisions must belong to the patient. Saks[19] also praises "the right to refuse medication,"[p 248] though noting that "medication has undoubtedly played a central role in helping me manage my psychosis."[p 331] All of the personal memoirs note the importance of relationships, including Jamison,[24] noting that without her mother "I never could have survived"[p 119] and Wurtzel[23] stating that "happiness is about community, intimacy, relationships, rootedness, closeness, family, stability, a sense of place, a feeling of love."[p 358]

Qualitative Studies

Dozens of qualitative studies of recovery and SMI have overlapping results.[10] One of the key findings is that, consistent with the autobiographical accounts above, recovery is considered as a journey of small steps that occurs even in the presence of symptoms.[25–28] As one study[27] participant said, "my strategy for succeeding is setting partial goals and sensible goals and realistic goals,"[p 186] while another study[29] participant identified "taking steps and trying to get back into a normal everyday life."[p 140]

Common across almost all of the qualitative studies of recovery is a finding that people with SMI consider a growing sense of agency and autonomy as central to recovery. One participant in a study stated, "I wake up every morning . . . and I have that power. I can control where I am going to go and what I am going to do with my life."[29, p 141] Another stated that "I believe you've got to help yourself."[30, p S72] This sense of control and responsibility, both inside and outside the mental health system, is considered a characteristic of recovery.[30–35]

Housing is one arena in which the deployment of such agency is vital. Numerous qualitative studies suggest that safe and secure housing is considered pivotal to recovery by people with mental illness, especially when they have exercised choice over type and location.[25,36–38] Tsai et al[39] note that their qualitative interviews revealed that "almost all clients want some form of independent housing,"[p 386] with one of his participants stating, "my ideal situation [is] to be self-sustaining, a regular part of the community, a place to live that I have the keys to."[p 385] Another qualitative study[27] noted that a salient recovery theme was a sense of home, with their data suggesting the importance of "a safe, private and secure space . . . for retreat, respite and renewal."[p 189] Indeed, the qualitative literature suggests that such a space provides psychological benefits beyond the obvious benefits of physical shelter. Numerous qualitative studies suggest that a home provides a place where people with mental illness can engage in positive withdrawal.[40,41] This can, in turn, promote the ontological security that fosters the strength and confidence to actively engage with the outside world.[38,42]

Another key arena of recovery suggested by the qualitative literature is employment. Numerous qualitative studies indicate that employment is considered a key facilitator (and indicator) of recovery, especially where there is client choice over type of employment.[29,43] One study[44] found that for people in recovery from SMI "the most commonly sought role was a worker."[p 332] This is echoed in another study[35] that noted the strong desire to work among study participants. A participant in another study[45] succinctly stated, "if I wasn't working my job I'd end up in the hospital or something like that—depressed all the time."[p 4] Participants throughout these studies noted that employment imparted the desired structure and meaningful social roles to their lives, facilitating community integration and sense of normalcy.[27,28] This met a common desire among study participants to distance

themselves from the mental health system; as one participant stated, "it was my choices . . . it wasn't anything centered around being a mental patient."[28, p 53] Work also imparted a sense of pride and self-esteem, expanded social networks, allowing participants to earn money and regain independence.

Another common theme throughout the qualitative recovery literature is that of social connectedness.[10,35,46] One study[44] reported that participants had "a longing for connection,"[p 328] while another study[26] witnessed social relationships as a decisive factor in recovery. One study[32] noted the importance of "being known, understood and accepted,"[p 4] while another identified the importance of supportive people.[21] Borg and Kristiansen's data[47] suggested that recovery was "a joint venture with a variety of helpers along the way."[p 501] Interestingly, numerous studies suggested the importance of peer support as an aspect of social connectedness.[26,28,44] One study[48] participant stated, in relation to peers, "we understand one another, we accept one another,"[p 178] while another study[29] participant stated that "it brings companionship and a feeling of equality and respect."[p 138]

Almost all qualitative studies suggest that recovery is enhanced by a mental health system that empowers people with SMI to make their own treatment decisions from a range of choices. This approach is characterized by "trust and respect rather than paternalism and coercion."[28, p 52] One study[47] found that clinicians become enablers in such a system, facilitating the autonomy considered critical by people in recovery. One participant in that study[47] stated approvingly about a psychiatrist,

> I found him so balanced . . . didn't have all kinds of programs of his own that we had to go through . . . I could talk about anything, everyday life things . . . I was the one who decided.[p 496]

Regarding medication, many participants noted that over-medication can be inimical to recovery, with one participant remarking, "I was a zombie."[28, p 52] Others noted that medications were only helpful when they had a strong say over the type and dosage. However, as Smith[25] noted, "it takes great courage to negotiate with the psychiatrist."[p 152]

Quantitative Research

As described above, people with SMI refer to recovery as a process or journey rather than an outcome, in contradistinction to typical clinical notions of recovery. Therefore, measuring recovery outcomes is problematic if the definitions described above are taken seriously. That said, a review of the outcome literature can give an insightful indication into the way recovery has been conceptualized in mainstream psychiatry, as well as the effect that the panoply of interventions have had on these notions of recovery. As such, in this section, we address large meta-reviews that have attempted to assess good recovery-related outcomes among people with SMIs over time.

Hegarty et al[49] conducted a meta-analysis of 320 studies that used widely differing definitions of good outcome (some clinical and some functional). Combined, they found 40% good outcomes and noted that the rate of good outcomes did not change according to era of study. Menezes et al[50] systematically reviewed 37 longitudinal studies of first-episode psychosis (with a mean follow-up length of 35 months), again using various definitions of outcome, and found 42% good outcomes. Both of these large reviews[49,50] lacked clear criteria for clinical and functional recovery and for the duration of good outcomes. Warner[51] attempted to improve the focus on recovery by reviewing 114 follow-up studies that included clear definitions of clinical recovery (loss of psychotic symptoms) and functional recovery (return to pre-illness level), but still without specifying duration of recovery. The findings showed a range of 11% to 33% recovery, again with no improvements in the rate of recovery in relation to era of study. Recently, Jääskeläinen et al[52] conducted a systematic review and meta-analysis of 50 longitudinal studies of people with schizophrenia, using criteria for clinical recovery, functional recovery, and duration of recovery (clinical or functional recovery lasting for at least 2 years). The median proportion of people fulfilling these criteria was 13.5%. No significant differences appeared in relation to sex, time of data collection, duration of follow-up, first-episode psychosis status, origin of the sample, and quality of the study. People from low-income countries had higher recovery rates, but only 5 studies (all confounded by people who dropped out or died) came from such countries. Only 4 of the 50 studies were epidemiologic, or population-based, samples rather than clinical groups.

Taken together, what do these systematic reviews tell us about clinical recovery? First, the rate of recovery, defined as good clinical and functional outcomes, has remained relatively low and unchanged during the past 100 years. Despite the appearance of antipsychotics in the 1960s, so-called second-generation antipsychotics in the 1980s and 90s, and various psychosocial evidence-based practices during several decades, recovery defined as sustained clinical and functional good outcomes remains an ideology without supporting data. Second, these studies assess outcomes, including clinical outcomes, rather than the process of moving toward independence and community integration, consistently identified as core aspects of recovery in the qualitative and autobiographical literature. As reviewed above, people with SMI define recovery as autonomy and agency, structure and meaningful activities, gainful employment, safe and secure housing, and empowering and humane relationships with treatment providers. We know much less about these variables when compared with variables related to symptoms and other clinical correlates.

Perhaps some of these processes have improved over time. More people with SMI now have the freedom to live outside of institutions, more are able to avoid medications and coercive mental health systems if they so choose, and more are able to pursue employment, friendships, and love

relationships in their communities.[4] However, these pursuits are clearly compromised by various inequities experienced by people with SMI.

Evidence suggests that many of these inequities are experienced precisely in the life domains self-defined as essential to recovery. For example, people with mental illness experience massively increased levels of homelessness and lack of access to safe affordable housing.[53] They experience extremely elevated rates of victimization,[54] and stigma remains at high levels, even in Western countries.[55] These are barriers to the process of recovery, especially impeding the desired community integration and social connectedness. They experience constant threats of coercion (sometimes by the criminal justice system, as well as the mental health system), perhaps increased by the current emphasis on community treatment orders and involuntary outpatient commitment.[56] In contrast, highly valued peer support remains an uncommon intervention.[57]

Indeed, the evidence that recovery is improving is minimal. Perhaps the most widely assessed recovery outcome is competitive employment—a primary goal for most people with SMI. Here the evidence shows that employment remains very low, at less than 20%.[58,59] Further, people with disabilities suffer greater job loss during recessions,[60] and employment rates have been declining, at least in the United Kingdom, where they have been measured consistently.[59] All this suggests that recovery aspirations and recovery realities remain discordant for many people with SMI.

Health Services

The most remarkable finding across the 4 large systematic reviews cited above[49–52] is the lack of improvement in outcomes over time, despite major changes in the delivery of care, such as deinstitutionalization, antipsychotics, psychosocial evidence-based practice interventions, and first-episode psychosis treatment teams. How can we understand this finding? Four possibilities arise. First, the samples, study procedures, and recovery criteria may have been so heterogeneous as to obscure meaningful differences. For example, even a simple outcome such as employment is inconsistently defined and measured across these studies. Second, the estimates may have been driven entirely by the natural course of the disorder and unaffected by treatments and services. In other words, variations in recovery rate estimates may depend on the strictness of the criteria rather than on the environment, including treatments. Thus the studies that estimated 40% to 42% recovery used less strict criteria than the studies that yielded a 13.5% estimate. Third, the inconsistent and problematic effects of treatments may have caused blurring rather than clarifying of outcomes. The most common treatment, antipsychotics, is widely acknowledged to be palliative rather than curative and to produce profound harms as well as to ameliorate psychotic symptoms. Meanwhile, specific psychosocial evidence-based practice treatments, which do enhance functional outcomes, are rarely delivered on any consistent, widespread basis, at least in the United States.[61] Fourth, we

may simply be measuring recovery in the wrong contexts. The existing studies have not occurred in systems of care that prioritize patients and their aspirations, but rather in systems that prioritize providers' and society's needs.

If we take seriously the grounded notions of recovery described in earlier sections of this paper, the implications for mental health services would be substantial. First, we should empower people to make decisions about life goals and treatments, encouraging them to self-manage their disorders as well as their own lives. Current evidence-based methods of facilitating such processes include the Illness Management and Recovery program[62] and the Wellness Recovery Action Planning intervention.[63] Another promising method of facilitating such management would be to distribute electronic self-management systems and self-referral systems directly to people with mental illness. They could then select the services they want from a list of choices.[64–66] Second, there are numerous evidence-based practice services that promote education, employment, housing, and social and spiritual opportunities. These include the Individual Placement and Support model of supported employment, which has been shown to be effective in 20 randomized controlled trials and several large demonstration projects.[67,68] They also include supported housing interventions, such as the Housing First evidence-based practice model.[69] Currently, these services are rarely available in real-world settings.[61] Nevertheless, given the right investments, many could be offered in peer centres, recovery centres, and other community settings that are well-placed to support people in their recovery goals.[70] Third, we should reduce or even eliminate institutional structures based on outdated models of care (including psychiatric hospitals and day treatment centres), given that research indicates that alternatives can be more effective and humane.[71] The money saved can be used to provide community supports and supported housing that is decent, affordable, and safe. Fourth, we would need to educate a new type of clinician and create renewed clinical systems that emphasize respect, alliance, freedom, choice, self-management, peer support, and facility with behavioural health technology. In such a system, treatment choices would be based on full information and shared decision making, promising approaches supported by evidence,[72] rather than on serving the needs of the pharmaceutical industry and professional guilds. We should also continue to fight stigma through targeted antistigma initiatives, and create further opportunities in society for people with disabilities through action and appropriate legislation.

To truly foster recovery, we should stop relabelling traditional clinical approaches, such as case management, skills training, and medications, as recovery-oriented. These interventions were rarely identified as core aspects of recovery in the qualitative and autobiographical accounts. Instead, we should develop and implement services that emphasize financial, residential, and personal independence; normal adult roles such as education, employment,

independent living, and intimate relationships, as well as personal agency and autonomy in illness management.

To conclude, we reaffirm that research stemming from rehabilitation science suggests that participation in many of the valued activities and social roles described in this paper can be enhanced by various evidence-based practice services. However, these types of services are rarely available. This is partly due to the vestiges of paternalistic thinking, and partly because funding is not often prioritized or aligned with such community-based, evidence-based practices.[73] These services are often defined as social or rehabilitative services, and delivered by underfunded systems that are sometimes separate from the health care system. Services that industry, professional guilds, vested interests, and unions prefer consistently gain funding to the detriment of services targeting the recovery domains identified as important by people with mental illness.[74] Society and policy-makers must recognize that medical solutions to social problems are expensive, ineffective, and inefficient. As such, closely integrating social and medical services would be humane, cost-effective, and truly recovery-oriented.

Acknowledgements

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