

## Remission and Recovery in Schizophrenia: Practitioner and Patient Perspectives

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Schizophrenia remains a complex, dynamic, multi-dimensional, and poorly understood condition. Although the concept of heterogeneity in outcome has conceptually overturned the post Kraepelinian legacy of progressive deterioration, a number of factors appear to contribute to perpetuating a pessimistic attitude toward outcome within the field. These include the limited access people with schizophrenia have to effective interventions and the phenomenon of the “clinician’s illusion,” which refers to the tendency of practitioners to assume that patients remain seriously ill when outside of the clinical care settings in which they are typically seen. Longitudinal studies, however, continue to point to a large number of people who experience improvements in their condition over time. Pressure from patients and their families, who experience periods of symptomatic relief and enhanced functioning first-hand, has led to the introduction of such concepts as “remission” and being “in” recovery with schizophrenia, in addition to the conventional notion of recovering “from” schizophrenia. These developments are consistent with recent policy initiatives by the U.S. and other governments around the world and aim to re-orient research and clinical practice from a traditional focus on effecting cure to exploring ways to encourage and assist people with schizophrenia to live meaningful lives in the face of an enduring illness.

**Key words:** remission/recovery/being in recovery

“The important thing ... is not to be cured, but to live with one’s ailments”

—Albert Camus, *The Myth of Sisyphus and Other Essays*<sup>1</sup>

### Introduction

Twenty-five years after Strauss and Carpenter<sup>2</sup> first published their interactive developmental model, schizophrenia remains a complex, dynamic, multidimensional, and

poorly understood condition. Although introducing the concept of “heterogeneity” over 20 years ago<sup>3</sup> countered the post-Kraepelinian pessimism concerning inevitable functional deterioration, the many studies carried out since have contributed little to accounting for such diversity in outcome. Advances in practice, while encouraging, continue to be limited in their range and effectiveness. Perhaps because of this, most interventions continue to be greeted with skepticism by patients and their families, continue to be inadequately funded and inexpertly delivered,<sup>4</sup> and continue to have high premature termination rates.<sup>5</sup> At the same time, longitudinal studies continue to report good outcomes for between 20% and 65% of each studied sample.<sup>6</sup> A proposal has recently been made for operationally defining “remission,”<sup>7</sup> and “recovery” has been heralded as the expected and expectable outcome for anyone inflicted with a serious mental illness by the President’s New Freedom Commission on Mental Health<sup>8</sup> and US government.<sup>9,10</sup> This report attempts to clarify some of these seeming contradictions by considering 2 different perspectives on several of the pieces of what remains a largely puzzling condition.

### Toward a Concept of Remission

A development from over 20 years ago offers a useful point of departure for our efforts to identify and understand some of the elements of this confusing picture. It was at that time that a pair of statisticians, Cohen and Cohen,<sup>11</sup> first introduced the notion of the “clinician’s illusion” to account for the tendency among practitioners, who treat ambiguous and prolonged illnesses, to assume that the ways in which such illnesses present in clinical care settings represent the ways these illnesses look both over time and among the broader population of persons afflicted with them. Based on a combination of advanced statistics and common sense knowledge that people who are neither acutely nor severely ill are less likely to access clinical care, the Cohens’ theory offered an explanation for how and why mental health professionals might retain their traditionally narrow and negative view of outcome in a condition like schizophrenia despite the accumulation of longitudinal data which suggests otherwise. Simply stated, when people are managing their condition adequately on their own they are much less likely to seek care.

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This insight is consistent with pieces of the clinical picture outlined below. We know that only about one-third of individuals experiencing a serious mental illness will access care from a specialty mental health setting,<sup>11</sup> meaning that those people having the most difficulty are most likely to be seen. We also know that few of these people will receive interventions that are evidence based or optimally effective<sup>4</sup> and few will adhere to the treatments offered to them over time.

On the other hand, we know from longitudinal studies that most people experience periods of symptomatic relief and functional improvement interspersed with periods of relapse or recurrence and that many of them experience significant and enduring longitudinal improvement. One additional dimension to this picture which the Cohens' may not have anticipated is that, once freed from the institutional culture of long-stay hospitals, many people with schizophrenia (and their families) have become intimately familiar with periods of relative symptomatic relief and functional improvement, as well as with positive overall outcomes, thereby not themselves being at high risk to succumbing to the clinician's "illusion." On the basis of such first-hand experiences, patients and families have, in fact, developed a different perspective on outcome in relation to schizophrenia, a perspective which has led to their bringing increasing pressure to the field toward abandoning traditional pessimisms.

For example, members of the "Remission Working Group" introduced the concept of remission in order to "incorporate the viewpoints of patients, caregivers, and clinicians" who argued for the need for "a positive, longer-term approach regarding outcome for patients with schizophrenia."<sup>7(p442, 448)</sup> The work group recently proposed a conceptualization of remission in schizophrenia parallel to that in affective disorders.<sup>7</sup> This concept captured patients' and family members' everyday experiences of the disorder, including that heterogeneity represents the rule rather than the exception in outcome. At one end of this broad spectrum, some studies have demonstrated that between 20% and 65% of people achieve a "good outcome" over time, ranging from mild impairment to functional recovery.<sup>3,6</sup> A small minority of people (under 20%) experience increasing impairments over time, whereas a sizable number experience sustained periods of symptomatic relief and improved functioning disrupted by episodes of recurrence or relapse. It is these periods of symptomatic relief and improved functioning which are now being described as representing periods of remission, and there is increasing recognition that such improvements are common.

According to the members of the Remission Working Group, such a remission can be characterized as:

a state in which patients have experienced an improvement in core signs and symptoms to the extent that any remaining symptoms are of such low intensity that they no longer interfere significantly with behavior and are below the thresh-

old typically utilized in justifying an initial diagnosis of schizophrenia.<sup>7(p442)</sup>

In other words, if a person has had a condition which was once severe enough to warrant a diagnosis of schizophrenia and that condition has since improved to the point at which it would no longer qualify for that diagnosis, then that person's condition can be said to have gone into remission. Such a state is labeled "remission" rather than "recovery" because, as the authors explain, the notion of recovery is understood to involve a "more demanding" and "longer term phenomenon" in which the person is "relatively free of disease-related psychopathology" and has the "ability to function in the community."<sup>7(p442)</sup> Like in other chronic illnesses, periods of remission may be time-limited, interspersed with periods of relapse or recurrence, and also do not constitute a full return to premorbid functioning. Remission, therefore, is described as "a necessary but not sufficient step toward recovery."<sup>7(p442)</sup>

### Recovery "from" and Being "in" Recovery

Introduction of the notion of remission represents a significant step away from the field's historical pessimism. Practitioners can convey hope that relief from the symptoms and functional impairments associated with schizophrenia is not only possible but also is obtainable by many people over time. But for many patients and families concern continues that this notion does not go far enough in conveying the optimism generated by longitudinal research. As noted by members of the working group, remission implies that the person is not yet recovered but remains vulnerable to relapse or recurrence. It represents, at worst, a tenuous hold on a temporary period of diminished illness severity or, at best, a stepping stone on the way to a fuller and longer term period of sustained recovery. Unless the concept of remission likewise is taken to be a transitional step for the field on the way to development of a concept of sustained recovery, then it will fall short of satisfying the demands of patients and their families.

Of course, it is not incumbent upon medical science to heed the demands of political movements. What is worthy to consider, however, is the experience base of patients and their families which has led to their developing a more positive approach to schizophrenia. These experiences, which were given voice in the Surgeon General's report<sup>11</sup> and the report of the President's New Freedom Commission on Mental Health,<sup>8</sup> have led to at least 2 understandings of recovery in relation to schizophrenia. The first described as recovery "from" schizophrenia is consistent with the conceptualization of recovery introduced by the remission working group, in which a person becomes "relatively free of disease-related psychopathology" and is able to "function in the community" over a prolonged period of time.<sup>7(p442)</sup> A few leading authorities in the field, such as Liberman and colleagues,<sup>12</sup>

have gone so far as to propose a set of operational criteria for this phenomenon, which, as noted above, occurs for between 20% and 65% of a given sample who are found to be symptom free and independently functioning at follow-up.

Because this sustained form of symptomatic recovery happens primarily outside of clinical settings, however, this form of recovery continues to have little reality for many practitioners. Indeed, such practitioners and scientists may scratch (or shake) their collective heads when they read position statements such as those found in the President's New Freedom Commission's final report, that "recovery... is now a real possibility...for everyone."<sup>8(p1)</sup> If this is the form of recovery to which such documents refer, then they are not supported by existing data and appear instead to represent empty political rhetoric because, at least for the foreseeable future, not everyone with schizophrenia will achieve this form of recovery. While post-Kraepelinian pessimism is no longer warranted, neither is a Pollyanna-like optimism that everyone will recover from schizophrenia.

What is missing in this argument is that the policy documents which preceded and followed the President's New Freedom Commission are political—not scientific—documents. Furthermore, they are not referring to this narrow, medical form of recovery. They are referring to another perspective on recovery which we describe as being "in" recovery.<sup>13</sup> This concept does not have as much to do with level of psychopathology as with how a person manages his or her life in the presence of an enduring illness. This form of recovery has been identified and described in various ways by mental health consumer advocates, psychiatric rehabilitation practitioners, and researchers.<sup>14–18</sup> Where all contributors seem to agree that this form of recovery refers to a unique and personal process rather than to a uniform end state or outcome and that it involves a person's self-determined pursuit of a dignified and meaningful life in the communities of his or her choice. The New Freedom Commission defined this form of recovery as "the process in which people are able to live, work, learn, and participate fully in their communities" and acknowledged that "for some individuals, recovery is the ability to live a fulfilling and productive life despite a disability."<sup>8(p5)</sup> Similarly, the American Psychiatric Association issued a position statement on the "use of the concept of recovery" stating that:

The American Psychiatric Association endorses and strongly affirms the application of the concept of recovery to the comprehensive care of chronically and persistently mentally ill adults ... Th[is] concept ... emphasizes a person's capacity to have hope and lead a meaningful life ... [and includes] maximization of 1) each patient's autonomy based on that patient's desires and capabilities, 2) patient's dignity and self respect, 3) patient's acceptance and integration into full community life, and 4) resumption of normal development. The concept of recovery focuses on increasing the

patient's ability to successfully cope with life's challenges, and to successfully manage their symptoms.<sup>19</sup>

With its focus on "chronically and persistently mentally ill adults" who have an ongoing need to manage symptoms, this position statement cannot liken being in recovery with schizophrenia to recovery from acute medical disorders. In fact, this form of being *in* recovery pertains to the 35%–80% of an ill population who do not experience full recovery over time. But if this second form of recovery is only applicable to people who do not recover, why is it called "recovery"? Surely this contradiction would lead to considerable confusion in the field, as it most assuredly has.<sup>13,18,20</sup>

Understanding this notion of being "in" recovery requires appreciating that the idea does not reflect a clinical or scientific reality as much as it does a social and political one. This notion of recovery was borrowed by the consumer movement from their counterparts in the addiction self-help community, who considered themselves to be "in recovery" as long as they were making active efforts to manage their sobriety and rebuild a meaningful life in the wake of their addiction. What appears to have been most appealing about this notion to people with schizophrenia was that their peers with addictions had been reclaiming their lives and the responsibility for making their own decisions even without first being cured of their condition. As there also is no cure for schizophrenia, people with serious mental illnesses argued in a similar vein that they should be able to reclaim their lives and autonomy without first having to recover from mental illness. As we noted in the quotation from Camus above, the important thing in this view is not to be cured but to live a meaningful and full life with "one's ailments."

It is this right to a self-determined and full life to which people remain entitled, and it is to this responsibility for managing the illness and dealing effectively with life's challenges to which they refer when people describe themselves as being "in" recovery despite the presence of an enduring mental illness. There are, of course, exceptions to this right to self-determination, just as there are in other forms of medicine. In psychiatry, this right remains intact except and until a person poses serious imminent risks to self or others, is gravely disabled, or is determined to be incapacitated by a judge.<sup>20</sup> In all other circumstances, people with serious mental illnesses retain the right to sovereignty over their person. As a result, to become recovery-oriented practitioners are expected to respect people in recovery as full partners in the treatment and rehabilitative enterprise, entitled to the same degree of collaborative, shared decision making, and informed consent as they and others are entitled to in other branches of medicine.<sup>21</sup>

Borrowing also from the physical disabilities movement, this form of being in recovery primarily involves people with "psychiatric disabilities" taking back their

lives in an active and purposeful fashion, pursuing their desires to “live, work, and participate fully in their communities,” rather than waiting for an eventual cure.<sup>22</sup> This is the form of recovery, presumably available to everyone, that is heralded in the New Freedom Commission report and other recent policy documents as it requires neither additional scientific breakthroughs nor advances in treatment or rehabilitation. What it requires, instead, is for people to take an active role in learning how to manage these illnesses and for society to view and treat people with serious mental illnesses as adults who are capable of doing so, as well as citizens who retain the right to make their own decisions—including the decision to describe their own challenges and victories in the terms of being “in” recovery—even while they remain disabled. These are experiences which appear to have become more common over the last 30 years of community life among people with serious mental illnesses and experiences which hopefully will become even more common in the future.

## Conclusion

Introducing the notions of remission and recovery reflect significant progress in the field of schizophrenia research and treatment. They are responsive in various ways to the experiences of patients and their families who have found that it is possible for many people to live meaningful and gratifying lives in the face of an enduring mental illness. The notion of being “in” recovery has been developed and promoted by people living with schizophrenia on their own behalf, and it captures the value they place on reclaiming their lives and their autonomy in the present rather than waiting indefinitely for some later time when they will be cured. There are 2 implications of such a perspective. First, it conveys hope to people with serious mental illnesses that improvements in their condition are possible and common. Second, while we cannot yet cure schizophrenia, we can continue to develop more effective interventions and, in the interim, can embrace the “revolution” in care<sup>10</sup> increasingly called for by governments around the world, a revolution which reorients services to helping people to take back up ordinary lives in the communities of their choice in the face of an enduring condition. While not everyone will recover from schizophrenia in the foreseeable future, it is possible that everyone will be able to engage in the recovery process, pursuing their own life goals autonomously and with dignity and purpose.<sup>23</sup> Exploring ways to support people in their efforts to do so opens up rich and challenging new vistas of intervention and opportunities for research.

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