8 A Model and Evidence Base for Achieving Complete Recovery in Schizophrenia

Ananda K. Pandurangi

Introduction

Schizophrenia is a persistent major mental illness that has been recognized in its current form for over 120 years. Throughout this period, a characteristic feature of schizophrenia has been a declining course, albeit to variable degrees in different individuals. It is generally agreed that about 65% or more of persons suffering from schizophrenia show a decline in social and occupational function. Despite much progress in pharmacotherapy and psychosocial therapies, the unfortunate fact remains that persons suffering from schizophrenia continue to be disabled [1]. The challenge to professionals, patients, and advocates is not only to research the cause, symptoms, course, and therapeutics of schizophrenia, but more importantly, embrace and develop a comprehensive approach of interventions that recognizes the full extent of the devastation created by schizophrenia. Adding insult to injury, in most societies, mental illnesses are severely stigmatized. Thus, the person suffering from schizophrenia is in triple jeopardy: from the illness, from lack of effective treatments, and from the stigma. The combined losses suffered as a result by the patient, and the range and severity of its full impact, beg a more meaningful and effective approach than is currently the standard.

Two major ingredients of such an approach have been recently labeled as clinical recovery and personal recovery [2]. Especially the recent development of concepts and interventions under the umbrella of personal recovery offer much promise in addressing this challenge. However, even this recognition may not be sufficient in and of itself, and a more comprehensive approach is needed. Such an approach is both desirable and possible. Most importantly, complete recovery may be the right of a person with schizophrenia.

Lost in Schizophrenia

To lay the foundations of an effective approach toward complete recovery first requires a comprehensive understanding of what is lost and is to be recovered. Traditionally, in training and clinical practice, it is recognized that the young person experiencing psychosis suffers losses in at least three domains: increasing loss of contact with the real world or so-called symptoms and behaviors of the illness, alienation from family and friends, and loss of abilities to function in expected role. These may be referred to as clinical losses. Families and professionals are quite aware of these losses. Less recognized in the scientific and professional literature until recently are more vital losses such as sense of purpose,

A. K. Pandurangi (✉)
Virginia Commonwealth University, Department of Psychiatry, Richmond, VA, USA
e-mail: apandura@vcu.edu

A. Shrivastava, A. De Sousa (eds.), *Schizophrenia Treatment Outcomes*,
https://doi.org/10.1007/978-3-030-19847-3_8

direction, and meaning in life and loss of self-esteem. Ultimately and tragically ones' dignity and humanity itself may be lost. These losses have been better recognized in nonfictional and documentary literature [3]. First-person accounts by literate patients vividly capture the blow to one's esteem and dignity that both schizophrenia and society's reaction to it cause them to suffer. The recognition, understanding, and interventions to recover both the clinical and personal losses constitute the complete recovery approach.

We list below the nature and range of these personal losses.

1. *Self-Reflectivity*: While a distinction is made between clinical deficits and personal losses, indeed this is arbitrary and simplistic. For example, metacognitive self-reflectivity is likely impaired in schizophrenia, heavily contributing to misperception and/or misinterpretation and consequently adding to the personal losses in hope and self-esteem [4]. Also see item 6 under Challenges in Implementing a Program for CR for more on this.
2. *Empathic Ability*: The individual's own ability to empathize might get impaired. This is often described by patients as "feel numb" and "feel no emotions." [5, 6] Awareness of this loss is most disturbing to the individual, leading to perpetuation of the "diminished" or "less than others" identity. For more on impaired empathy, see item 5 below and in the section *Approach to Complete Recovery,* item9.
3. *Sense of Control*: Does the person with schizophrenia feel any degree of control over his or her life? Schneiderian First-Rank Symptoms often seen in schizophrenia emphasize loss of ownership of one's thoughts and feelings. Psychological and somatic passivity are part of this experience. Adding to this subjective loss of control are the dry and technical nature of professional assessments, infantilizing responses, and societal fears and harsh regulations (example: persons with schizophrenia are violent and be transported in hand cuffs); all conspire to reduce the individual to a helpless and sick individual, someone with no will and autonomy.
4. *Hope and Faith:* Yet another personal loss in schizophrenia is that of hope and faith. These are the very values that help us survive and drive us to excel. It appears that the combination of losses, both clinical and personal described above, make a severe dent in the ability to feel hope and have faith in oneself, one's family, providers, community, and even a higher spirit [7]. Studies have indicated that persons with schizophrenia often experience a sense of not belonging or alienation and lack of parental or God's love toward them, ultimately leading to loss of faith [8, 9].
5. *Diminished Self:* Persons with schizophrenia often see themselves as "diminished" compared to their own previous self and less than others [10]. Perceived correctly or incorrectly, their ongoing experience validates this and further reinforces them. Even worse, an unfortunate consequence of stigma is that it often gets internalized, resulting in shame making the individual his or her own victim. An additional complication arises when the result of shame is depression [11]. Ultimately, respect as an individual is not experienced, and the person's dignity as a human being and member of society is endangered. Once a unique individual with aspirations and vitality now becomes a shadow of oneself.

In laying a firm foundation to a successful recovery approach, all stakeholders would do well to appreciate the above losses, the complexity and nuances of these losses, and the dynamic interplay between clinical and personal losses.

Clinical Recovery

The targets of clinical recovery pertain to the well-recognized symptoms, behaviors, and deficits of schizophrenia. This is understandable given the very disruptive nature of these symptoms and behaviors, the severely limited resources within the mental health-care delivery systems, and the absence of proven causes and pathology of schizophrenia. Most pharmacotherapies target hallucinations, delusions, and disorganized

behavior, and psychosocial therapies focus on ensuring basic survival supports. Only about 65–70% of patients benefit from current medications in the reduction of positive symptoms. Sustainable outcomes with long-term antipsychotic treatment is not fully established, and substantial questions remain about their role in full recovery [12]. In the last two decades, we have recognized other symptoms and behaviors, such as negative symptoms and cognitive impairments, as relevant targets for therapy, although as of now no effective treatment exists for these domains. Within clinical recovery, the emphasis had been mostly on symptomatic recovery rather than functional recovery, until about early 2000. As cognitive impairments were recognized as barriers to functional recovery, projects such as MATRICS were developed to standardize tests and assessment methods, and better define these deficits, as well as suggest therapeutic targets. Research continues both in pharmacology (to develop newer compounds with newer mechanisms of action such as glutamate modulation) and in psychosocial therapies such as cognitive mediation and cognitive behavior therapy to address these limitations. None of these well-intentioned, well-studied interventions can currently claim to reverse or overcome the core deficits of schizophrenia and the ensuing disabilities. Most importantly, such pharmacological and psychosocial therapies do not adequately address the personal losses described in the earlier section.

Complete Recovery

We describe here the concept of complete recovery (CR) to include clinical, functional, personal and material recovery, with subjective and objective dimensions as applicable, and based on a fundamental principle of acceptance of the person with schizophrenia as a complete individual with dignity and respect.

A major challenge to studying the progress toward CR is that there is significant variation in terms and definitions used to describe outcomes. These terms include symptomatic response, symptom resolution, symptomatic and functional remission, recovery, clinical recovery, personal recovery, etc. The Remission in Schizophrenia Working Group (RSWG) reviewed the literature and published operationalized criteria which are heavily focused on symptomatic remission in 2005 [13]. Even with narrower definitions of remission, rates of clinical recovery/remission vary widely, likely due to varying methods of assessment and patients moving in and out of remission. In one review, the range was as wide as 17–88% [14]. A 2013 meta-analyses of 50 studies indicated the median remission rate to be 13.5% [15]. Thus, it is evident that a substantial number of persons with schizophrenia do not experience full recovery [16]. However, this disappointing statistic should not deter us from building a complete recovery program.

The CR definition proposed here may appear daunting to achieve. Can an individual, after having suffered from schizophrenia and lost not only cognitive and emotional abilities but dignity and respect, hope to attain a state of CR? The recovery movement differentiated clinical recovery, related to the disorder's symptoms and behaviors, from personal recovery, consisting of a state of feeling well, feeling in control, and feeling hopeful. Based more on the latter concept of recovery, a process gathered momentum that has been termed the Recovery Movement. Many concepts best described as positive psychology were incorporated into this. Negative aspects such as hopelessness, lack of joy, and suicidal feelings were put into a wider perspective that included a more positive self-image and self-esteem and sense of control. Resilience emerged as something very possible for the person with schizophrenia, who now was seen as accepting and adapting to the illness and its impact rather than being passive and hopeless. More importantly, this approach created a sense of purpose and direction to work towards. This opens the possibilities of feeling happy, being satisfied, and being a full person. The emphasis shifts from dealing with symptoms and avoiding relapse to managing one's life and setting goals and direction like every other human being [17]. A recent review of empirical evidence about recovery concluded that rather than frame a

person's outcome in terms of symptoms and disability assessed by professionals, it is possible to adopt a positive framework and approach how to *live well* despite mental health problems, to de-emphasize diagnosis as a constant label, and be flexible with regard to treatment, including the fact some people may not need formal medical treatment [18]. An important aspect of the complete recovery state is the ability to experience happiness. There have been suggestions that people with schizophrenia can experience an overall sense of happiness in their lives [19] and happiness can be a goal of therapy. Likewise, subjective well-being is also very possible in persons with schizophrenia [20]. Thus, CR appears to be achievable.

The central core of recovery may be conceived of as a sustained state of mind wherein the person experiences acceptance, dignity, and respect. This aspect of recovery is similar to insight. It is understood that such a state is not absolute and can vary with circumstances, events, and people. However, models and treatment approaches that assess a person as being sick, or judge as being impaired, cannot be part of any recovery model. All therapies aiming at recovery should understand and accept this fundamental principle. Most importantly, such subjective recovery is critical to proceeding toward recovery in the other more objective domains. Another analogy might be that of the victim with trauma, such as sexual trauma or torture. Can such a person ever feel like a complete human being again? In schizophrenia, while the trauma is not a single discrete event, the sheer persistence of the losses and society's reaction constitute severe trauma. True CR under current conditions might not be achievable in most, but we will not know to what extent we can achieve it, unless a CR model is accepted and built, resources are allocated, training is accomplished, and therapies are developed, fine-tuned, and implemented. A note of caution regarding recovery and insight: CR does not require the person to develop complete insight, often considered a positive mental health attribute and a target of therapies. The role of insight in recovery is controversial because of the dynamic interplay between insight and many attributes of recovery. Insight may have undesirable effects on self-esteem and motivation and could hinder recovery [21]. There may be unintended consequence of insight, with a tragic outcome such as suicide [22].

Approach to Complete Recovery

We outline here 10 elements needed for a successful complete recovery approach.

1. *Developing the Model*: An important initial step is the full development of the complete recovery model. Complete recovery has not been the target of any of the current approaches. While secondary and tertiary prevention as traditionally defined in Medicine focus on reducing morbidity through physical, vocational, and social rehabilitation, the recent recovery-based approaches focus on finer psychological aspects such as illness education (psychoeducation), stress management, social skills, and fellowship, as well as encourage providers to be patient-centered and allow/encourage patient autonomy. However, none of the current approaches include acceptance and restoring dignity as the central goals. This is indeed hard to achieve in the current care delivery systems, especially in Western countries. These systems are reimbursement-based, and payers do not ascribe any relative value units (RVU) to helping one feel human. The focus is often on diagnosis and treatments to reduce symptoms and prevent hospitalization. For example, a 30-minute walk in the park between the therapist and the "patient" as between friends is not reimbursable, yet such an activity is crucial to complete recovery. To a limited extent, activity coaches are available and focus on specific daily activity; peer counselors aim to improve illness understanding and acceptance of treatment; therapists strive to enhance stress management and coping, crises management, adaptation to the illness, etc.; and doctors focus on reducing core

symptoms, achieving behavioral stability, and reducing hospitalization. Nowhere do we hear in lectures, classes, treatment algorithms, or outcome measures the words dignity, respect, esteem, and humanity. Only in patient satisfaction reviews and first-person accounts do we see these phrases: "I did not feel respected." "I was judged." "The police treated me like an animal." "I was lost, who am I?" "I am a shadow, not a real person." "Everyone was looking at me like I was an alien," etc. Therefore, the complete recovery model needs to be embraced by the profession, researched, and promoted. Resources and reimbursements will need to be aligned with the model.

2. *Development of Instruments*: This is a key step in implementing the model. There are sufficient scales to assess clinical recovery, but very few for personal recovery. Thirteen instruments that include elements of personal recovery in the context of schizophrenia or schizoaffective disorder were reviewed in a study which concluded that the Recovery Assessment Scale (RAS) was thought to be the best currently available measure of personal recovery [23]. It has 38 items covering personal confidence, hope, goals, mastering illness, being connected, and the sense of belonging [23]. There are also other instruments to assess recovery [24] that especially focus on subjective awareness of symptoms.
3. *Identifying Basic QOL Needs*: While we have focused on the personal losses and clinical losses, not to be forgotten is the material losses. Many persons with schizophrenia just do not have the basic necessities of life, and any attempt at recovery that does not address these basic needs will fail. Numerous studies across the world have documented housing and employment needs of persons with schizophrenia. As many as 75% of such persons go without social supports and/or access to employment. Monetary support, social engagement, and employment are the most important needs for people with psychotic illness, as well as good physical and mental health. These are to be the foundational elements of the CR approach [25–28].
4. *Utilizing Current Knowledge and Evidence-Based Therapies*: There is no inherent conflict with biologically based knowledge of the illness and therapies and the principles of recovery. In fact, they can build on each other. It has been recommended that the latest knowledge of the neuroscience of schizophrenia be utilized in developing a new bio-psycho-socio-behavioral model for treatment [29]. Such a model would recognize the limitations and gaps in current knowledge, for example, a poor understanding of the biology of negative symptoms and lack of treatments for the same [29]. It is beyond the scope of this chapter to list effective biological or psychosocial therapies. Making such therapies accessible and available is also a required part of the CR model. We only mention here that cognitive remediation techniques in particular may help address the metacognitive impairments and allow better participation by the patient in all aspects of his/her care. Other psychosocial therapies currently with adequate evidence base and/or promising include assertive community treatment (ACT), cognitive behavior therapy (CBT), family psychoeducation, social skills training, cognitive adaptive therapy, and social skills training [30, 31].
5. *Use of Patient-Centered Terminology/Language*: Before proceeding too far in developing the recovery approach, it is to be emphasized the art of appropriate communication is critical to this approach. No matter how good the intentions might be, if the person with schizophrenia does not feel invited as a participant through the use of appropriate, sensitive, and respectful language, our attempts are likely to fail. Sometimes, such language has been termed "person-first language" [32].
6. *Recovery Settings*: The recovery approach needs to be practiced in all settings and not just the counselor's office. This is especially important in inpatient settings. While engaging the person when he/she is most unwell

seems challenging, however studies indicate it can be accomplished. The risk of not engaging the person actively in the recovery process during the acute stages of illness is that recovery-oriented dialogues will not have any credibility. Engaging with former inpatients, role-play, mentorship, and learning recovery processes go hand in hand with specific symptomatic treatments [33].

7. *Consumer Perspective and Subjective Assessments*: Assessments, scales, interventions, and outcome measurements need to have a strong consumer perspective. Prior studies indicate consumers are more interested in personal well-being, social inclusiveness, and self-management and less in clinical recovery measures [34, 35]. However, it is likely that there are relations between subjective measures of personal wellness and objective elements relating to observable symptoms [36].
8. *Role of Peers*: While peer counseling has been accepted as a valuable tool in reaching the person with psychosis, it remains severely underutilized for various reasons, most importantly reimbursement. Both direct peer support and peer-led family education as well as peer-operated services should be integral parts of a recovery-based approach [37]. Peers can provide mutual support/self-help and consumer-operated services. Also see item 7 in the section *Implementing a Program for Complete Recovery* for more on peer counseling.
9. *Autonomy and Shared Decision-Making*: Another key element of a successful recovery approach is the practice of shared decision-making (SDM). We have referred to loss of control as a key loss in schizophrenia and its consequences. While many illness/therapy models acknowledge this, care delivery systems have largely ignored the process of SDM. In part, it is due to the nagging concern that a person with schizophrenia is not capable of such decisions. However, such a concern is not empirically validated. Further, interventions exist such as metacognitive training to enable the sufferer to overcome cognitive impairments and actively participate in SDM [38]. In fact, psychosocial programs have been developed with a curriculum to assist the patient with illness management [39]. Also see the section *Implementing a Program for Complete Recovery* for more on illness management.
10. *Recovery as a Right*: Finally, in developing and implementing the complete recovery model, it should be recognized that recovery with all its individual elements is the right of the person with schizophrenia. This includes both recovering the clinical, functional, personal, and material losses.

Challenges to Implementing a Complete Recovery Program

Implementation of the above CR model faces many challenges. These can be systematically overcome by a thoughtful plan with the participation of all the stakeholders. Several challenges have already been alluded to, such as the rigidity of the reimbursement systems and disincentives to personalizing care. Unfortunately, there are more ingrained challenges to overcome. Some are beyond the scope of this chapter, such as the historical roots and misunderstandings of the nature of mental illness. We list below 10 challenges that create barriers to complete recovery. This is a selective list and is not exhaustive.

1. *Lack of Education*: A lack of understanding of the basics of mental illness among health professionals and community stakeholders including leadership, and most importantly the person with schizophrenia, is a critical weakness. Ignorance or outdated knowledge among our own colleagues is painful and embarrassing. In health profession schools, mental illnesses and their treatment are either inadequately taught or stigmatized. Trainees may even be discouraged from choosing careers in the mental health field. A strong reorientation of the educational curriculum, and continuing education of the educators and school leadership, is needed. While

medical and other schools are incorporating human values in the curriculum, we have moved too far in the direction of laboratory and radiological studies, short hospital stays, high throughput, and defensive medical practices to seriously consider giving a central place in our curriculum to human suffering and patient respect. As said above, these are not reimbursable. For this and other reasons, personal losses are mostly ignored in medical school and other education. That chronic illness takes away something more than health and (material) productivity needs to be seriously recognized.

There is also a very significant lack of education within the community, including within the leadership, as to the nature and enormity of mental disorders and their consequences to the individual and the family/community. This knowledge deficit acts as a major barrier in making resources available to improve access, create an appropriate workforce, and provide a continuum of services that address the losses mentioned in the earlier section. Mental health professionals need to join with patients and their families in understanding that schizophrenia is not a malignant disease that inevitably deteriorates over time but rather one from which most people can achieve a substantial degree of recovery [40].

While educating professionals and community is critical, such knowledge will lead to limited results unless the consumer is well informed of the nature of his/her own condition. Most persons with schizophrenia simply experience and suffer while not knowing the basics pertaining to their illness and its impact on their lives [41]. Stigmatizing perceptions may be reduced by receiving information about symptoms, diagnosis, medications, therapies, etc. Therapies like CBT serve both educational and therapeutic purposes [42, 43].

2. *Stigma*: Stigma puts a choke hold on recovery. While stigma is a complex and multilevel challenge, it has a direct negative effect on any attempt to recover the personal losses necessary for complete recovery. As long as society does not fully understand or believe that schizophrenia is a brain disease and no different from any other chronic major medical illness, the challenges to complete recovery will remain. In a study of 16 countries, with regard to stigma concerns with childcare, perceived potential for violence, fears of unpredictable behavior, reservations about marrying into the family, and children's access to education emerged as common concerns resulting from stigma [11]. Stigma discourages from seeking care, impedes access, and enables noncompliance, but most importantly, the false basis of stigma begins to appear real to the afflicted person. This seriously challenges recovery. It is almost impossible to genuinely recover if family, friends, and/or the community at large believe that mental illness is a personal weakness; a made-up, imaginary, or fake condition; an attention-seeking manipulation, etc. Under such beliefs, it is difficult to make a case for empathy or convince that the victim of schizophrenia is deserving of the same respect that all human beings deserve. Also see prior discussion on the toxic role of stigma in the section *Lost in Schizophrenia*, item 5.
3. *Access*: Any progress in understanding the nature of schizophrenia and the losses suffered is negated if there is no access. Less than 50% of persons with a mental disorder seek help, less than 50% of those seeking help have access to such help, and less than 50% of those having access get the full range of services needed. Without a warlike effort to improve access, our hopes for recovery will remain only that. Both stigma and shame hinder access. Shame discourages help seeking and often leads to depression, isolation, and alienation. Guilt forms another dimension of this quadruple challenge. The quad of stigma, shame, guilt, and depression soon lead to loss of hope and further alienation and often end in suicide [44]. Sense of belonging and hope have been identified as vital for recovery [9].

4. *Human Resources*: A very significant challenge with relevance to all other aspects discussed here is the absence of qualified workforce, both medical and nonmedical. For complete recovery to be realistic, access, support, and understanding are needed from providers. The notion that assessment, medication, and supportive therapy complete a quality program is seriously flawed. While these are certainly key ingredients of a quality service, they are but ultimately an inadequate answer to the challenges of schizophrenia. A workforce that is educated and trained in the full spectrum of losses suffered in schizophrenia is needed. Each discipline needs to transform its curriculum to adequately understand the trauma and loss inflicted by this mental illness. To achieve this requires significant resources and possibly a reorientation of our health education priorities and curricula.
5. *Media*: We now live in a very different world than 50 years ago. The mentally ill person no longer lives hidden in a basement. However, the public at large is just as mystified and terrified of schizophrenia as it was then. This is unfortunate, and the blame may be squarely laid at the foot of the various health professions and media for this. Review of media continues to show significant negative, dramatized, and ill-informed coverage. Understandably, this directly impacts on what/how the public, community, and leadership understand mental illness to be. It negates any effort the professions may make in correctly informing the public about serious mental illnesses. There may be light at the end of this tunnel, and there is some indication that media articles now are becoming less stigmatizing [44].

   The personal losses mentioned earlier are by themselves significant challenges and are discussed below. However, in order to restore them, the above listed more tangible challenges need to be addressed first.
6. *Metacognitive Impairments*: We have alluded to impaired metacognition in schizophrenia. Such impairment limits the ability to be self-aware emotionally, cognitively, and socially and thus have a pervasive negative influence on attempts at recovery. Motivation is dulled. It is not uncommon to hear persons with schizophrenia say they do "nothing" with their time. Whether such a mental state itself perpetuates positive symptoms of hallucinations or paranoia, or so-called internal stimuli, is a good question [6, 46, 47]. Also see prior discussion on this topic in the section *Lost in Schizophrenia*, item 1, and in the section *Challenges to Implementing a Complete Recovery Program*, item 7.
7. *Impaired Empathy*: Impairment in the ability to empathize is a significant challenge. Among other things, this ability allows the individual to be connected, to be trusted, and to put in perspective one's suffering with that of others. Studies indicate deficits in empathy for persons with schizophrenia. For example, interpersonal reactivity index may be blunted, albeit less so in females with schizophrenia [5].
8. *Loss of Control*: Earlier, it was indicated that loss of control is one of the unfortunate end products of the consequences of schizophrenia. Loss of volitional control is a central feature of the Jasperian and Schneiderian criteria for the psychotic experiences of schizophrenia. However, over and above these fundamental experiences, lack of understanding of the nature of the disease, misunderstanding its impact, and maladaptation by patient, family, and society all contribute to the creation of loss of control in the individual. Persons with schizophrenia often identify an external locus of control. Both psychotherapeutic and psychosocial recovery approaches are necessary to restore some degree of control within the individual. Adherence/compliance and recovery approaches are likely to fail if this loss is not adequately addressed [7].
9. *Loss of Faith, Religion, and Spirituality*: Yet another critical factors in ensuing progress toward complete recovery are faith, religion,

and spirituality. These provide a foundation for connecting with fellow beings, in having a sense of structure, and in creating a sense of higher purpose. Persons with schizophrenia often lose faith in fellow human beings and in God and may feel working toward a higher purpose in life is beyond them. They may feel cheated of the basic freedoms of life and conclude that their family does not love them, that God does not love them, that they are lesser beings who could not possibly aspire for higher goals in life, etc. Caregiver love, nurturance, and love of God are reported as very important in continuing to live and recover [8, 56].

10. *Maladaptive Coping*: As unfortunate and challenging as the disease might be, it is the inability to cope with the impact of the disease that actually determines the outcome and eventually extent of recovery. Well-intentioned but ineffective coping strategies result in frustration, disappointment, negative emotions, and burnout. Both culture and education and health-care organizations influence how people cope with schizophrenia and other major illnesses. It is likely that the finding from WHO studies that less developed and more rural countries have a better prognosis in schizophrenia may very well be a result of both acceptance and more natural coping styles [48].

Implementing a Program for Complete Recovery

The future for implementing programs to achieve complete recovery is bright. This is despite the challenges and limitations listed above. In part, this optimistic view is made possible by increasing knowledge in psychiatric neuroscience, neuropsychology, and social psychology; by increasing awareness of recovery; and, most importantly, by increasing advocacy. We list below 10 elements of a successful recovery program. This list is selective and not exhaustive or complete.

Utilizing Advances in Neuroscience and Psychosocial Sciences for Education and Treatment Development

Our best opportunities are coming both from neurosciences and psychological sciences such as personal psychology, trauma psychology, etc. The former is shedding light on the pathophysiology of hallucinations and delusions, on the neural basis of the chaos that the person with schizophrenia has to endure and struggle through, and in the development of biological therapies, for example, new glutamatergic agents, theta burst magnetic stimulation, etc. The psychosocial sciences help us understand impairments in working memory, social cognition, metacognition, etc. as well as the personal losses of self-esteem, hope, faith, respect, dignity, etc. that were listed in the earlier sections. These developments will enhance our knowledge of the challenges a person with schizophrenia faces and the treacherous road they are traveling on and offer some solutions. Rather than get lost in a black hole of symptoms and behaviors that appear odd and irrational, providers will be able to appreciate the underlying neurophysiology and psychology of the symptoms and behaviors of psychosis and the personal struggles of the sufferer. Such understanding should serve as the foundation of a complete recovery program.

Other sciences that are contributing to a better understanding of what it takes for a complete recovery include personal psychology, trauma psychology, and human ethics. These are informing us of the uniqueness of each individual, styles of cognition, perception, interaction and behavior, experience, and vulnerabilities of the traumatized individual. Another source of learning will be through recent innovations in psychosocial approaches to serious mental illness including patient autonomy, patient centeredness, first-person language, peer counseling, etc. These are compelling us to think beyond symptoms, diagnosis, and prescription or mere verbal support. (See prior discussion of this topic in the section *Approach to Complete Recovery*, item 4.)

Ethical studies help us understand that every individual has a right to recovery and to be treated with respect and dignity. There will no doubt be a positive fallout on both societal leaders and community stakeholders from such new knowledge. This, it is hoped, will transform their views of mental illness and lead to better resources. More importantly, it is hoped this will change society's reaction to the individual with schizophrenia. Increased awareness and better understanding within all stakeholders could translate into more resources, more research, better treatments, better access, and less stigma, setting the stage for true and full recovery of the individual with schizophrenia.

Creating Therapeutic Alliance

Another fundamental characteristic of a strong recovery program is the therapeutic alliance. While not a new concept by any means, creating therapeutic alliances, incorporating the approach of patient autonomy and patient centeredness can be challenging to traditional practitioners and systems. However, studies indicate that a greater degree of recovery orientation, reduced stigma, and more awareness of these on the part of the client and therapist help create better therapeutic alliances [49]. Strong therapeutic alliance allows the therapist to substitute his/her ego resources for the impairments of the person with schizophrenia and creates the platform to effectively address the other personal losses.

Treatment Setting

The terms *recovery*, *approaches to recovery*, and *recovery programs* seem to be more associated with outpatient/community care. While clearly the bulk of recovery should happen in such settings, the seeds have to be sown in all settings, and especially in acute and step-down programs, crisis stabilization centers, partial hospitalization, and other day programs. While this appears daunting because of the severity of the condition and perceived lack of readiness for recovery, as well as limitations of short length of stay, multiple studies have demonstrated the feasibility and the value of implementing recovery approaches in such settings. Marked improvements in symptom management, functioning, social connectivity, and self-confidence have been noted [50].

Vocational Rehabilitation, Employment, and Housing

Another critical aspect of a complete recovery program is the attention and emphasis on vocation. The material and psychological impacts of not having a vocation and job contribute heavily to personal loss, especially control and self-esteem. Access to vocations is not simply a matter of providing a referral or performing an intake. Appropriate psychological and hands-on support is needed throughout the vocational process [51]. Clearly, vocational rehabilitation not only provides a job and income but also improves self-care, reduces social isolation, creates a sense of autonomy, and has a cascading positive effect on the ability to overcome other impairments such as in planning and budgeting. Mapping one's time is another critical need for many persons with schizophrenia, and having a vocation is one way of achieving this [4]. There had been significant hindrance to recovery from the practice that one ought to be clinically stable before housing could be obtained/provided for a person with schizophrenia. Housing First initiatives have done away with such mistaken notions and are imperative in a successful CR program. Cross mapping of resources within a catchment area goes a long way in identifying all the available resources, helps decision-making in where to put resources, and avoids duplication.

Technology

A major source of support for recovery is coming from developments in technology. Technological tools help in all aspects of recovery, from access (tele-psychiatry), compliance (smartphone reminders), self-help blogs and online support

groups, easy access to mental health videos and films, etc. Use of technology can be an integral part of illness education and management [52].

Mobile Services

Meeting the patient where he/she is both literally and functionally is a central principle of recovery. From the older concept of house calls to the recent intensive or assertive community treatment methods, mobile services can be helpful in improving access, treatment compliance, transportation challenges, crisis intervention, relapse, and hospitalization prevention as well as address personal losses of isolation/alienation. Clinicians working with mobile services can also help clients manage their own illnesses better and develop healthier lifestyles [53].

Peers

Reference has been made to the emerging role of peers in the recovery process. This appears to benefit both the index patient and the peer counselor. It is now well established that peers add a unique new value toward engagement, adherence, improvement, and recovery of a person with serious mental illness. We have not yet tapped the full potential of this resource. Both paid and volunteer peer services are now becoming available. Several aspects of such services need continued study and refinement, such as confidentiality/privacy, conflicts of interest, individual bias, supervision of the peer counselor, etc. Nevertheless, studies supporting the role and value of peer services are growing and indicate the value and benefits of such services [54]. (Also see prior discussion in the section *Approach to Complete Recovery*, item 8.)

Self-Reflectivity

Impaired metacognition including self-reflectivity poses significant challenge in achieving recovery goals. The ability to learn about oneself including past experiences is a critical element toward complete recovery. Techniques are being developed to improve or overcome this handicap. For example, both cognitive remediation techniques and manualized narrative psychotherapy have been shown to produce specific improvements in persons with schizophrenia. (Also see prior discussion on this topic in the section *Lost in Schizophrenia*, item 1, and *Challenges to Implementing a Complete Recovery Program*, item 6.)

Illness Management

While traditionally clinicians have directed the management of psychiatric illness, it has become more evident that illness management by the patient with schizophrenia is both feasible and highly desirable and contributes significantly to progress toward more complete recovery. Such management is a joint effort between providers and patients. Patients are encouraged to learn to identify symptoms and behaviors, manage them, and learn techniques to cope with triggers, benefits of compliance, relapse prevention, etc. Peer support and counseling are especially important in this regard [55]. (Also see the section *Approach to Complete Recovery*, item 9, for prior discussion of this topic.)

Spirituality

We have earlier described the role of spirituality in the recovery process. There is no single method of incorporating spirituality into a recovery program. Faith- and religion-based services, nondenominational services, yoga, and other meditation practices are all available. The critical element is not any one method but the realization that such practices instill a sense of hope, connectivity, and a higher sense of being—elements that are often severely hurt in schizophrenia. Clients may regard spirituality as a source of giving and receiving love and care, and professionals may regard it as a means of receiving support and managing symptoms [31, 56]. Such differeing

goals may easily be reconciled to optimize the benefits.

In this chapter, we have provided a model for complete recovery and examples of evidence-based methods of implementing such a model. However, it is acknowledged that many more significant topics that impact recovery are not addressed here. These include, but are not limited to, the role of substance use, medical comorbidities, challenges around behaviors of aggression and violence, and self-injurious and suicidal behaviors. Also not addressed in the model building is legislative advocacy. Lastly, we have not included the burden on families and supports needed, which are also part of a total recovery program. A comprehensive model would certainly include these challenges and current recommendations and evidence-based interventions to address them.

Conclusion

Schizophrenia is a devastating chronic disease afflicting at a young age and robbing the person of what every other person takes for granted—a healthy, productive, and satisfying human life. Attempts over the last 100+ years have been to understand the biology and psychopathology of this disease and mitigate its symptoms, reduce hospitalization, and improve function. Largely forgotten in these otherwise worthwhile and appropriate efforts is a range of personal losses suffered by the individual. The disease and society together rob the individual of his/her dignity and humanity. Complete recovery involves the identification, understanding, and recovery of the full range of losses suffered by the person with schizophrenia, especially the personal losses. We have presented the range, scope, and nature of these losses, and challenges and opportunities in creating an approach and a model to recover them, and outlines of a program with the goal of complete recovery. Continued research into the neuroscience of schizophrenia, major changes in our educational curricula and field training, war-like effort against stigma, and a thorough understanding of the personal losses are needed to achieve this goal. All measures and targets of outcome and all approaches to recovery need to continue vigorously, but always with the understanding that it is about our fellow human being, and not just a patient or client. It is just as important to foucs on who and what is recovered as on how much is recovered. Complete recovery is very possible if such transformative changes can be accepted and implemented.

References

1. Hegarty JD, Baldessarini RJ, Tohen M, Waternaux C, Oepen G. 100 years of schizophrenia – a meta-analysis of the outcome literature. Am J Psychiatry. 1995;151:1409–16.
2. Cavelti M. Assessing recovery from schizophrenia as an individual process. A review of self-report instruments. Eur Psychiatry. 2012;27(1):19–32.
3. Allen S. A kind of mirraculas paradise: a true story about schizophrenia. New York: Simon and Schuster; 2018.
4. Bonfils KA, Lysaker PH, Minor KS, Salyers MP. Affective empathy in schizophrenia: a meta-analysis. Schizophr Res. 2016;175(1–3):109–17. https://doi.org/10.1016/j.schres.2016.03.037.
5. Bonfils KA, Lysaker PH, Minor KS, Salyers MP. Empathy in schizophrenia: a meta-analysis of the Interpersonal Reactivity Index. Psychiatry Res. 2017;249:293–303. https://doi.org/10.1016/j.psychres.2016.12.033.
6. Bonfils KA, Luther L, George S, Buck KD, Lysaker PH. The role of metacognitive self-reflectivity in emotional awareness and subjective indices of recovery in schizophrenia. J Nerv Ment Dis. 2016;204(12):903–8.
7. Stanghellini G, Bolton D, Fulford WK. Person-centered psychopathology of schizophrenia: building on Karl Jaspers' understanding of patient's attitude toward his illness. Schizophr Bull. 2013;39(2):287–94. https://doi.org/10.1093/schbul/sbs154.
8. Prout TA, Ottaviano P, Taveras A, Sepulveda C, Torres J. Parental and god representations among individuals with psychosis: a grounded theory analysis. J Relig Health. 2016;55(6):2141–53. https://doi.org/10.1007/s10943-016-0265-0.
9. Barut JK, Dietrich MS, Zanoni PA, Ridner SH. Sense of belonging and hope in the lives of persons with schizophrenia. Arch Psychiatr Nurs. 2016;30(2):178–84. https://doi.org/10.1016/j.apnu.2015.08.009.
10. Lysaker PH. Schizophrenia and alterations in self-experience: a comparison of 6 perspectives. Schizophr Bull. 2010;36(2):331–40.
11. Keen N, George D, Scragg P, Peters E. The role of shame in people with a diagnosis of schizophrenia. Br J Clin Psychol. 2017;56(2):115–29. https://doi.org/10.1111/bjc.12125.

12. Harrow M. Does long-term treatment of schizophrenia with antipsychotic medications facilitate recovery? Schizophr Bull. 2013;39(5):962–5.
13. Andreasen NC, Carpenter WT Jr, Kane JM, Lasser RA, Marder SR, Weinberger DR. Remission in schizophrenia: proposed criteria and rationale for consensus. Am J Psychiatry. 2005;162:441–9.
14. Emsley R. The concepts of remission and recovery in schizophrenia. Curr Opin Psychiatry. 2011;24(2):114–21.
15. Jääskeläinen E, Juola P, Hirvonen N, McGrath JJ, Saha S, Isohanni M, et al. A systematic review and meta-analysis of recovery in schizophrenia. Schizophr Bull. 2013;39(6):1296–306. https://doi.org/10.1093/schbul/sbs130.
16. Harvey PD. Functional impairment in people with schizophrenia: focus on employability and eligibility for disability compensation. Schizophr Res. 2012;140(1–3):1–8.
17. Bozikas V, Parlapani E. Resilience in patients with psychotic disorder. Psychiatriki. 2016;27(1):13–6.
18. Slade M, Longden E. Empirical evidence about recovery and mental health. BMC Psychiatry. 2015;15:285. https://doi.org/10.1186/s12888-015-0678-4.
19. Palmer BW, Martin AS, Depp CA, Glorioso DK, Jeste DV. Wellness within illness: happiness in schizophrenia. Schizophr Res. 2014;159(1):151–6. https://doi.org/10.1016/j.schres.2014.07.027.
20. Fervaha G, Agid O, Takeuchi H, Foussias G, Remington G. Life satisfaction and happiness among young adults with schizophrenia. Psychiatry Res. 2016;242:174–9. https://doi.org/10.1016/j.psychres.2016.05.046.
21. Cavelti M, Rüsch N, Vauth R. Is living with psychosis demoralizing? Insight, self-stigma, and clinical outcome among people with schizophrenia across 1 year. J Nerv Ment Dis. 2014;202(7):521–9. https://doi.org/10.1097/NMD.0000000000000160.
22. Jahn DR, DeVylder JE, Drapalski AL, Medoff D, Dixon LB. Personal recovery as a protective factor against suicide ideation in individuals with schizophrenia. J Nerv Ment Dis. 2016;204(11):827–31.
23. Hancock N, Scanlan JN, Bundy AC, Honey A. Recovery Assessment Scale – Domains & Stages (RAS-DS) manual- version 2. Sydney: University of Sydney; 2016.
24. Corriveau DP, Sousa S. Levels of Recovery Scale (LORS): psychometric properties of a new instrument to assess psychotic symptoms and patient awareness. Psychol Rep. 2013;113(2):435–40.
25. Munikanan T, Midin M, Daud TIM, Rahim RA, Bakar AKA, Jaafar NRN, et al. Association of social support and quality of life among people with schizophrenia receiving community psychiatric service: a cross-sectional study. Compr Psychiatry. 2017;75:94–102. https://doi.org/10.1016/j.comppsych.2017.02.009.
26. Carmona VR, Gómez-Benito J, Huedo-Medina TB, Rojo JE. Employment outcomes for people with schizophrenia spectrum disorder: a meta-analysis of randomized controlled trials. Int J Occup Med Environ Health. 2017;30(3):345–66. https://doi.org/10.13075/ijomeh.1896.01074.
27. Morgan VA, Waterreus A, Carr V, Castle D, Cohen M, Harvey C, et al. Responding to challenges for people with psychotic illness: updated evidence from the survey of high impact psychosis. Aust N Z J Psychiatry. 2017;51(2):124–40. https://doi.org/10.1177/0004867416679738.
28. Kim YK, Choi J, Park SC. A novel bio-psychosocial-behavioral treatment model in schizophrenia. Int J Mol Sci. 2017;18(4):pii:E734. https://doi.org/10.3390/ijms18040734.
29. Saperstein AM. Current trends in the empirical study of cognitive remediation for schizophrenia. Can J Psychiatr. 2013;58(6):309–10.
30. Mueser KT. Psychosocial treatments for schizophrenia. Annu Rev Clin Psychol. 2013;9:465–97.
31. Jensen ME. Championing person-first language: a call to psychiatric mental health nurses. J Am Psychiatr Nurses Assoc. 2013;19(3):146–51. https://doi.org/10.1177/1078390313489729.
32. Kidd SA, McKenzie KJ, Virdee G. Mental health reform at a systems level: widening the lens on recovery-oriented care. Can J Psychiatr. 2014;59(5):243–9.
33. Jose D, Ramachandra, Lalitha K, Gandhi S, Desai G, Nagarajaiah. Consumer perspectives on the concept of recovery in schizophrenia: a systematic review. Asian J Psychiatr. 2015;14:13–8. https://doi.org/10.1016/j.ajp.2015.01.006.
34. Siu BW, Tsang MM, Lee VC, Liu AC, Tse S, Luk HS, et al. Pathway to mental health recovery: a qualitative and quantitative study on the needs of Chinese psychiatric inpatients. BMC Psychiatry. 2016;16:236. https://doi.org/10.1186/s12888-016-0959-6.
35. Jørgensen R, Zoffmann V, Munk-Jørgensen P, Buck KD, Jensen SO, Hansson L, et al. Relationships over time of subjective and objective elements of recovery in persons with schizophrenia. Psychiatry Res. 2015;228(1):14–9. https://doi.org/10.1016/j.psychres.2015.03.013.
36. Duckworth K. Peer support and peer-led family support for persons living with schizophrenia. Curr Opin Psychiatry. 2014;27(3):216–21.
37. Chan KK, Mak WW. Shared decision making in the recovery of people with schizophrenia: the role of metacognitive capacities in insight and pragmatic language use. Clin Psychol Rev. 2012;32(6):535–44.
38. Roosenschoon BJ, Mulder CL, Deen ML, van Weeghel J. Effectiveness of illness management and recovery (IMR) in the Netherlands: a randomised clinical trial. BMC Psychiatry. 2016;16:73. https://doi.org/10.1186/s12888-016-0774-0.
39. Zipursky RB. The myth of schizophrenia as a progressive brain disease. Schizophr Bull. 2013;39(6):1363–72.
40. Ahmed AO, Marino BA, Rosenthal E, Buckner A, Hunter KM, Mabe PA, et al. Recovery in schizophrenia: what consumers know and do not know.

Psychiatr Clin North Am. 2016;39(2):313–30. https://doi.org/10.1016/j.psc.2016.01.009.
41. Schlier B, Lange P, Wiese S, Wirth A, Lincoln T. The effect of educational information about treatments for schizophrenia on stigmatizing perceptions. J Behav Ther Exp Psychiatry. 2016;52:11–6. https://doi.org/10.1016/j.jbtep.2016.02.002.
42. International First Episode Vocational Recovery (iFEVR) Group. Meaningful lives: supporting young people with psychosis in education, training and employment: an international consensus statement. Early Interv Psychiatry. 2010;4(4):323–6.
43. Pescosolido BA, Medina TR, Martin JK, Long JS. The "backbone" of stigma: identifying the global core of public prejudice associated with mental illness. Am J Public Health. 2013;103(5):853–60. https://doi.org/10.2105/AJPH.2012.301147.
44. Whitley R, Wang J. Good news? A longitudinal analysis of newspaper portrayals of mental illness in Canada 2005 to 2015. Can J Psychiatr. 2017;62(4):278–85. https://doi.org/10.1177/0706743716675856.
45. Luther L, Firmin RL, Minor KS, Vohs JL, Buck B, Buck KD, et al. Metacognition deficits as a risk factor for prospective motivation deficits in schizophrenia spectrum disorders. Psychiatry Res. 2016;245:172–8. https://doi.org/10.1016/j.psychres.2016.08.032.
46. Cella M, Edwards C, Wykes T. A question of time: a study of time use in people with schizophrenia. Schizophr Res. 2016;176(2–3):480–4. https://doi.org/10.1016/j.schres.2016.06.033.
47. Rexhaj S, Jose AE, Golay P, Favrod J. Perceptions of schizophrenia and coping styles in caregivers: comparison between India and Switzerland. J Psychiatr Ment Health Nurs. 2016;23(9–10):585–94. https://doi.org/10.1111/jpm.12345.
48. Kvrgic S, Cavelti M, Beck EM, Rüsch N, Vauth R. Therapeutic alliance in schizophrenia: the role of recovery orientation, self-stigma, and insight. Psychiatry Res. 2013;209(1):15–20. https://doi.org/10.1016/j.psychres.2012.10.009.
49. Frost BG, Turrell M, Sly KA, Lewin TJ, Conrad AM, Johnston S, Tirupati S, Petrovic K, Rajkumar S. Implementation of a recovery-oriented model in a sub-acute Intermediate Stay Mental Health Unit (ISMHU). BMC Health Serv Res. 2017;17(1):2. https://doi.org/10.1186/s12913-016-1939-8.
50. Pańczak A, Pietkiewicz I. Work activity in the process of recovery – an interpretive phenomenological analysis of the experiences of people with a schizophrenia spectrum diagnosis. Psychiatr Pol. 2016;50(4):805–26. https://doi.org/10.12740/PP/44238.
51. Thomas N, Farhall J, Foley F, Rossell SL, Castle D, Ladd E, et al. Randomised controlled trial of a digitally assisted low intensity intervention to promote personal recovery in persisting psychosis: SMART-therapy study protocol. BMC Psychiatry. 2016;16(1):312. https://doi.org/10.1186/s12888-016-1024-1.
52. Naslund JA, Marsch LA, McHugo GJ, Bartels SJ. Emerging mHealth and eHealth interventions for serious mental illness: a review of the literature. J Ment Health. 2015;24(5):321–32. https://doi.org/10.3109/09638237.2015.1019054.
53. Kidd SA, McKenzie K, Collins A, Clark C, Costa L, Mihalakakos G, et al. Advancing the recovery orientation of hospital care through staff engagement with former clients of inpatient units. Psychiatr Serv. 2014;65(2):221–5. https://doi.org/10.1176/appi.ps.201300054.
54. van Langen WJ, Beentjes TA, van Gaal BG, Nijhuis-van der Sanden MW, Goossens PJ. How the illness management and recovery program enhanced recovery of persons with schizophrenia and other psychotic disorders: a qualitative study. Arch Psychiatr Nurs. 2016;30(5):552–7. https://doi.org/10.1016/j.apnu.2016.04.005.
55. Ho RT, Chan CK, Lo PH, Wong PH, Chan CL, Leung PP, et al. Understandings of spirituality and its role in illness recovery in persons with schizophrenia and mental-health professionals: a qualitative study. BMC Psychiatry. 2016;16:86. https://doi.org/10.1186/s12888-016-0796-7.
56. Huguelet P, Mohr SM, Olié E, Vidal S, Hasler R, Prada P, et al. Spiritual meaning in life and values in patients with severe mental disorders. J Nerv Ment Dis. 2016;204(6):409–14. https://doi.org/10.1097/NMD.0000000000000495.