

Creative Solutions to Overcoming Barriers in Treatment Utilization An International Perspective

Wulf Rössler

Abstract

Despite the noteworthy changes in the provision of mental health services in all industrialized countries, there are still considerable deficits in the treatment and care of persons with mental illness. This is particularly true for those with serious illnesses such as schizophrenia as one- to two-thirds of all severe cases of mental disorders go untreated.

This chapter addresses the determinants of help-seeking behavior and methodological issues related to the assessment of needs for care. Help-seeking behavior is affected by (a) prior personal experiences in looking for assistance, (b) the social environment and the influence of significant others, and (c) the overall disease and treatment concepts of the individual. Several approaches taken toward reducing the proportion of untreated persons in need of help are discussed, ranging from a general political level to more specific health care policy. Finally, strategies are discussed for improving the way in which mental health professionals can shape their personal relationships with patients and learn to respect their ideas about the causes of their disorder so as to include them in all treatment decisions. In mental health care, the relationship between patient and therapist is one of the most important treatment factors, serving as a reliable predictor of outcome, regardless of diagnosis, setting, or type of therapy used.

Introduction

Remarkable changes have been made in how mental health services are provided in all industrialized countries where large state-run mental hospitals have been downsized in favor of outpatient services within communities. This process of deinstitutionalization has not only brought a shift of financial resources

from inpatient to outpatient care, it has also been accompanied by a significant increase in those resources (Gustavsson et al. 2011). Furthermore, major developments have occurred in the pharmacological, psychotherapeutic, and psychosocial treatment of mentally ill persons.

Several surveys of the general population have revealed that a high prevalence of mental disorders can create an enormous burden for disease management (Rössler 2006). It also has become clear that many persons with such disorders do not use or do not receive mental health services tailored to their objective treatment needs (Alonso et al. 2004, 2007; Bijl et al. 2003; Kessler et al. 2005; Saldivia et al. 2004). For example, Bijl et al. (2003) analyzed the prevalence rates and treatment estimates from Canada, Chile, Germany, the Netherlands, and the United States—all countries with considerable variance in their mental health treatment settings. Estimates for 12-month prevalence (i.e., the proportion of a population under investigation that has experienced a mental disorder during the past year) range between 17.0% (Chile) and 29.1% (United States). Treatment rates vary significantly across countries, from a low of 7.0% in Canada to a high of 20.3% in Germany, with a U.S. rate of 10.9%. Prevalence rates and overall treatment rates show no direct relationship. Although the probability of receiving treatment is strongly related to the severity of the disorder, between one- to two-thirds of all persons with serious cases obtain no treatment in a given year (Bijl et al. 2003). Undertreatment of serious cases is most pronounced among young, poorly educated males.

European countries show considerable differences in their use of drug and psychotherapy treatments, which are difficult to explain. For example, in Great Britain, almost 40% of all treated patients are given medication, but the proportion of patients receiving psychotherapy is comparatively low (about 12%). By contrast, just over 15% of patients in Denmark with mental health problems receive medication. Overall, the proportion of people who undergo psychotherapy because of mental problems is much smaller (10–20%) than for those who get medication. The fact that nonspecialists rarely provide medication and psychotherapy demonstrates the severe undertreatment of such disorders in primary care (OECD 2012).

These high rates of unmet needs have provoked critical discussion over the structure of psychiatric and psychosocial services. Potential reasons for mentally ill persons not receiving mental health services according to their needs can range from the individual (e.g., a patient's subjective perception of the illness, a caregivers' influence, questions of demand and supply, socioeconomic factors, or the impact of society, such as that pertaining to stigmas associated with mental illnesses) to questions about the appropriateness of professional services that are offered.

In this chapter, this topic is approached from several perspectives. We begin with a general discussion of what is meant by the concept of “unmet needs.” Thereafter we focus on those needs for severely mentally ill patients, in general, and for persons with schizophrenia, in particular.

The Concept of Needs

The concept of needs is intuitively quite appealing. It implies that we have a checklist available for the objective criteria of “need.” The starting point for such a need evaluation is the prevalence rate of mental illness in the general population.

Over the last few decades, highly structured research interviews were developed that allow a reliable assessment of mental symptoms and, consecutively, the identification of “cases” in large population samples. Over time, modifications to these assessment instruments have revealed their sensitivity to seemingly small changes and, likewise, their limitations when defining needs for care and treatment (Regier et al. 1998). Unfortunately, due to differences in the construction of these instruments, some of the best-known general population surveys have produced quite different rates for individual disorders (Andrade et al. 2003; Andrews et al. 2001; Bijl and Ravelli 2000; Jenkins et al. 1997; Kessler et al. 2003; Regier et al. 1993). Regier et al. (1998) compared two large-scale surveys conducted in North America at approximately the same time: the Epidemiological Catchment Area Study (ECA) and the National Comorbidity Survey (NCS). For ECA, they calculated selected prevalence rates of 4.1%, 4.2%, 9.9%, 1.1%, and 1.6% for diagnoses of alcohol dependency, major depression, anxiety disorder, panic disorder, and social phobia, respectively; in NCS, prevalence rates were 7.4%, 10.1%, 15.3%, 2.2%, and 7.4%. Similar differences were found when lifetime prevalence rates were compared.

It is difficult to interpret such diverging figures and to identify the magnitude of the population in need, if we do not assume that those values indicate true differences. It is much more likely that the difficulties in making a reliable case assessment contribute the most to those differences (Cooper and Singh 2000). However, not only do these contrasting data raise concerns about the comparability of different studies, assessments which reveal consistently high rates also invite serious questions about the clinical significance of all of these disorders. Thus far, this (epidemiological) discussion has made clear that the recourse to symptoms is not sufficient when defining a group of persons in need (Wittchen 2000). DSM-IV included clinical significance criterion, which requires that symptoms cause “clinically significant distress or impairment in social, occupational, or other important areas of functioning.” This rule attempts to minimize false-positive diagnoses in situations where the symptom criteria do not necessarily indicate pathology on pragmatic grounds. This argument has been particularly emphasized in the discussion over the revision of the DSM-5 (Regier et al. 2013).

Because most human behavior is located along a continuum, no clear cutoff point exists to separate good health from illness and, as such, define a point where the need for treatment exactly begins. Instead, categorical classification systems do not represent natural illness entities but, rather, constitute agreed-upon definitions for designating a (certain) mental illness on pragmatic grounds.

This continuum approach has been widely accepted for affective disorders (Angst et al. 2003). Comparable emerging debate now concerns psychotic disorders. Within a general population, van Os et al. (2009) have calculated a rate of about 5% for psychotic symptoms that are below the threshold of a psychotic disorder (see also Rössler et al. 2013)—a percentage which is five times higher than that reported for full-blown schizophrenia.

From a professional perspective, a significant proportion of persons with subclinical psychosis display mental symptoms which are, to a varying degree, accompanied by functional disability. Using data gathered over a period of 30 years from a community cohort in the Canton of Zurich, we have concluded that those symptoms are associated with significant dysfunction in social roles (Rössler et al. 2007). These symptoms are of clinical importance because their presence may increase the risk for comorbid mental disorders (Rössler et al. 2011), including those related to substance use (Rössler et al. 2012). In terms of schizophrenia spectrum disorders, the reference population is obviously much larger than has been commonly assumed. Because persons affected at a threshold below that of a psychosis diagnosis are subjectively distressed and in need of help, it is quite likely that physicians “upgrade” the symptomatology to a respective psychiatric diagnosis, which then officially allows them to pursue psychiatric treatment.

Determinants of Help-Seeking Behavior

Help-seeking behavior by an individual is affected by prior personal experiences in looking for assistance, by the social environment and the influence of significant others, and by the overall disease and treatment concepts of that individual. To evaluate these concepts as a whole, Lauber et al. (2000) conducted a representative population survey in Switzerland with a detailed focus on lay opinions about mental disorders and their treatment options (Lauber et al. 2001). Respondents were presented with two vignettes based on DSM III-R: one described depression; the other, schizophrenia. Respondents were then asked for their impressions about what might be helpful in treating those disorders. Respondents could choose from a list of health services and professions, while also selecting various individual treatment measures. Overall, 68% chose “psychologist” first, followed by “family doctor” (57%) and “psychiatrist” (51%). After “psychotherapy” (42%), “inpatient treatment” or individual treatment measures (e.g., “medication” or “electroconvulsion therapy”) were recommended by less than 20%. Within a similar magnitude, “homeopathy” (19%) or “natural remedies” (20%) were also proposed.

The answers differed with respect to the two vignettes. A larger portion of the respondents recommended consulting a “psychiatrist” for schizophrenia than for depression. Furthermore, drug proposals varied, with the public

distinguishing between antidepressants and antipsychotics. "Psychiatric hospitalization" and "psychotherapy" were considered to be more helpful for schizophrenic persons than for depressive individuals. However, antipsychotics, "psychiatric hospitalization," and "psychotherapy" were considered more harmful for depressive than for schizophrenic individuals.

With regard to the different diagnoses, it was crucial when suggesting a treatment to know if the disorder was perceived as a "life crisis" or a "disease." Those respondents who considered the person to be in a life crisis preferred nonmedical interventions such as "social workers," "telephone counseling," "naturopaths," and "homeopathy." They opposed standard psychiatric therapy that included "psychiatrists," "psychopharmacology," and "psychiatric hospitalization." However, if the described person was perceived to be mentally ill, respondents recommended significantly more traditional psychiatric intervention strategies ("psychiatrist," "psychotherapy," and "psychopharmacology"). Furthermore, treatment strategies viewed as an alternative to traditional medicine (e.g., "naturopaths" or "vitamins") that were also used "to deal with the situation alone," were viewed as harmful.

Such concepts must necessarily have an impact on help-seeking behavior. First, it is striking that laypeople have confidence in individual persons and not treatment measures. Above all, family physicians (and, in Switzerland, also psychiatrists) appear trustworthy; their treatment methods, however, are seen as significantly less reliable. The fact that the professional group "psychologist" and the method of treatment "psychotherapy" received the most nominations makes clear that most people want nonstigmatizing professional help. Pharmacological treatment obviously is considered in opposition to such a concept because it implies that those affected will lose control over their lives when using medication. This is also suggested by the general linguistic usage concerning medication: "chemical straitjacket" or the "tranquilization" of a person.

Against this attitudinal background, an affected individual—often in accord with their family or other important caregivers—then decides in a second step whether and what help he or she wants to utilize. Because financial barriers in Central European health systems do not play a major role in this decision-making process, so-called "convenience factors" shape a person's help-seeking behavior. One well-analyzed factor is the distance or travel time to a required institution. Approximately 40 years ago, a German Expert Commission assumed that a service user would accept a travel time of one hour. However, as several of our own analyses have shown, this threshold is far too high for psychiatric patients. In fact, travel time of just a half hour reduces the number of willing users by 50%. This applies to both outpatient (Rössler et al. 1991) and inpatient care (Meise et al. 1996). Thus, the decision to engage a health service is caught in a delicate balance, as demonstrated by the short-term decline in the utilization of psychiatric emergency services in Scotland during the 1990 Football World Cup (Masterton and Mander 1990).

Socioeconomic Factors

Other factors that influence individual help-seeking behavior include those grounded in the social and environmental living conditions of potential users. The environmental perspective refers to the social characteristics of a geographical region, whereas the social perspective describes the individual psychosocial characteristics of those persons affected. Analyses about how socioeconomic factors affect the onset and course of mental disorders, as well as the utilization of (mental) health services, have a long tradition in social-epidemiological research. Since the pioneering work of Faris and Dunham (1939), the association between social factors and the development of mental disorders has been discussed controversially. Nevertheless, the relationships between indicators of deprivation (mostly socioeconomic indicators of difficult living conditions combined with a lack of social support) and help-seeking behavior are well documented and, in health planning, widely accepted (Folwell 1995; Gaebel et al. 2012; Lancet Global Mental Health Group et al. 2007).

Stakeholders

Unlike most other medical disciplines, agreement has been scarce in the field of psychiatry among patients, caregivers, and professionals over the causes of mental disorders and how they should be treated.

Professionals

By law, in all European and Anglo-Saxon countries, the task of an objective needs assessment lies with a physician. In general, that assessment must precede the making of any decision over a treatment, which must then be labeled “necessary,” “sufficient,” and “appropriate.” If no treatment type can address a need appropriately, then one deems this to be a “no (objective) need.”

Objectives defined by professionals, however, do not necessarily correspond to those of patients. Physicians often seek to relieve a symptom, a goal they see as a necessary and sufficient prerequisite for a better quality of life. For patients, however, functional integration into family, work, and society is of utmost importance (Eichenberger and Rössler 2000).

To make things worse, psychiatrists are not the natural allies of persons with a mental illness. At best, psychiatrists hold the same opinion about them as does the general public (Lauber et al. 2004a). If we assess the attitudes of psychiatrists who work in institutional settings, we find that they confirm even more stereotypes about patients (especially with respect to patients with schizophrenia) than does the general public or even other professional groups who are involved in such treatment and care (Nordt et al. 2006).

To ensure that psychiatric treatment is effective, it is crucial to improve cooperation between patients and psychiatrists. We already know that a better

therapeutic relationship between the two parties is associated with closer adherence to medication among patients with schizophrenia (McCabe et al. 2012). In mental health care, the relationship between patient and therapist is one of the most essential treatment factors, serving as a reliable predictor of treatment outcome, regardless of diagnosis, setting, or type of therapy used. Any perceived loss of autonomy will accompany a more negative dynamic between patient and clinician (Theodoridou et al. 2012).

This relationship is not necessarily restricted to the dyadic situation between a patient and one therapist, nor does it focus exclusively on clinical outcomes. The therapeutic relationship is quite often extended to an entire team or several members of that team. Thus, a good relationship improves quality of life for the patient in general and vocational outcomes in particular (Catty et al. 2010, 2011).

Patients/Users/Caregivers

Concepts of disease and treatment diverge between patients and professionals and can result in significant tensions. This is especially true for families with a member who suffers from schizophrenia. To address this, various psychoeducational programs have been developed to enhance understanding of schizophrenia, to provide information about various treatment options, and to enrich their coping strategies to deal with crises more successfully. The overall objective has been to reduce a families' burden (Dixon et al. 1999).

From their perspective, caregivers for schizophrenic patients prefer early and prompt (inpatient) treatment over a sufficient length of time, because a significant proportion of caregivers experience physical violence prior to an acute exacerbation of the disease (Lauber et al. 2003). By contrast, patients often try to avoid inpatient treatment or opt for minimum care which takes the least amount of time. Caregivers often require detailed information about the course of treatment, which may not be disclosed to them without the consent of the patient. In the case of (premature) discharge from inpatient treatment, family members desire the broadest possible support for their caring responsibilities.

Some of this may explain the different attitudes of patients and caregivers toward medications. Caregivers prefer, whenever possible, to use depot medication to gain control, whereas patients themselves want maximum autonomy concerning their treatment (Jaeger 2010). For reasons of convenience, depot medication might be, for patients, a reasonable alternative to oral medication. However, on the whole, the degree to which an intervention is acceptable to a patient cannot be ignored (Perkins 2001).

Above all, patients seek to gain self-esteem. The concept of empowerment also entails being able to exercise control over a treatment through self-determination and participation (Scott et al. 1999). These dimensions are strongly correlated with quality of life (Rogers et al. 1997). Although these considerations are part of the British health policy (Lelliot et al. 2001), they

are not applied consistently when the primacy of evidence-based medicine is postulated during the selection process of various treatment approaches.

The concept of empowerment, self-determination, and active participation in treatment has led to a new view of the course of serious mental illnesses, particularly schizophrenia. While professionals have for many decades held very pessimistic opinions about the course of schizophrenia, it is quite clear today that there is a remarkable heterogeneity of outcomes for persons with that disease. Even if many of the affected do not return to premorbid functioning, most afflicted persons have a good chance for symptom remission, independent living, vocational integration, intimate relationships, etc. Many services are now available that have adopted such a recovery-oriented view for patients (Farkas 2007).

Public

The general public holds quite specific ideas about mental disorders and the objectives of psychiatric treatment. Their attitudes are determined by their discomfort against the mentally ill, which then leads to demands for utmost security. In the above-mentioned representative population survey in Switzerland, more than 70% of respondents favored compulsory treatment in the case of mental illness (Lauber et al. 2002). Between 60% and 75% said that a driver's license should be revoked in such cases, while 26% to 39% proposed that a pregnant woman should consider an abortion if she has ever suffered from a severe mental disorder. In addition, between 19% and 34% of the overall population has recommended that the right to vote be withdrawn in the event of a mental disorder (Lauber et al. 2000).

These wide-ranging expectations for psychiatric treatment and care make it clear that, in terms of resource allocation, psychiatry cannot have top priority. However, where the security needs of the population are very high, the public believes that considerable investments can be made (e.g., in the case of drug addicts or sex offenders) to ensure that such persons are excluded or marginalized from general societal life. All of this makes clear how urgently we need more public education about schizophrenia and other serious mental illnesses to reduce their attendant stigma and discrimination.

Cost-Benefit Ratio

Accompanying these tense relationships between patients, medical staff, and the population at large is another dimension: cost-benefit ratios. For efficient use of resources, it is essential to choose treatment methods with the best ratio. For example, when assessing schizophrenia treatments, we can either increase the vulnerability threshold (drugs or psychosocial means) or reduce environmental stresses (e.g., via sheltered work and housing). Drugs are highly effective in preventing relapses and can also be applied in psychosocial treatments,

albeit to a lesser extent. Mojtabai et al. (1998) have demonstrated in a meta-analysis that a combination of medication and psychosocial treatment delivers the best results. From a health economics perspective, however, the gap is wide among costs associated with these different approaches. Out of the overall cost for treating schizophrenia, sheltered living and working environments account for approximately 40% of the annual totals, while the expense of drugs amounts to only about 6% (Salize and Rössler 1996; Salize et al. 2009). Although the costs of psychotropic medication for treating schizophrenia have tended to remain at that level, a recent cost analysis of six European countries (Salize et al. 2009) has demonstrated a 12-fold difference in the total treatment costs for schizophrenia between the “cheapest” and “most expensive” country. That difference is mostly due to the costs of sheltered living and working in those places.

Overcoming Barriers in Treatment Utilization

Each year, one- to two-thirds of all serious cases of mental disorders go untreated (Bijl et al. 2003). Several significant factors that influence help-seeking behavior, such as structural deterrents to service utilization or attitudinal barriers by the general public, could be addressed at a political level.

Financial barriers do not play a compelling role in precluding utilization in Central Europe: almost 100% of the population is covered by health insurance, and the public generally has free and equal access to all health services. In other parts of the world, including the United States, objective problems arise in providing and, consequently, taking advantage of mental health services.

A remarkable attitudinal change has occurred in some portions of Europe, especially toward affective disorders, for which there has been a major shift in de-stigmatization. This development can be attributed to the fact that the general public acknowledges today that affective symptoms are part of our everyday life, whereas psychotic symptoms seem to refer only to a very small proportion of the population. The emerging topic of subclinical psychosis has allowed professionals to convey to citizens the sense that psychosis is much more widespread in the general population than has historically been thought: (subclinical) psychosis is something that may apply to one's own family and is not something that usually happens only to others.

From a health policy perspective, it seems advisable to broaden the concept of psychosis, because resource allocation in health care follows the idea that financial resources will be preferably placed where we expect the highest health gains for the general population. An enlarged concept increases the proportion of the general population who might be affected and, likewise, improves the probability that those financial resources will be invested toward caring for psychotic disorders.

To reduce the stigma attached to mental illness, we must demonstrate the advantages of a life-crisis model concerning the onset of mental disorders when compared to a disease model. The general public perceives environmental stressors to be a significant source that impacts the onset of those disorders. Media coverage of “burnout” has contributed to that process because it reflects these lay opinions. However, the appeal of a concept such as burnout does not (yet) extend to schizophrenia, which has been conceptualized more as a disease (Lauber et al. 2002). By applying the ideas of subclinical psychosis, where environmental factors are more prevalent (Rössler et al. 2007), the life-crisis model could be promoted in the same manner, thereby leading to greater (societal) acceptance of persons with schizophrenia.

The existence of burnout allows mental health workers as well to take a different view of their own profession. Several studies have identified stressors that are unique to the psychiatric field. These challenges range from the stigma of the profession, to particularly demanding relationships with patients and difficult interactions with other mental health professionals as part of multidisciplinary teams, to personal threats from violent patients. Other sources of stress are a lack of positive feedback, low pay, and a poor work environment. Finally, patient suicide is a major stressor, upon which a majority of mental health workers report posttraumatic stress symptoms (Rössler 2012).

In clinical practice, professionals could encourage better help-seeking behavior by improving the way in which they shape their personal relationships with patients, respect their ideas about the causes of their disorder, and include them in all treatment decisions. In mental health care, the relationship between patient and therapist is one of the most important treatment factors, serving as a reliable predictor of outcome, regardless of diagnosis, setting, or type of therapy used (Theodoridou et al. 2012). Professionals should also reconsider their attitudes toward those with mental illness. Rather than revering the deficit model of schizophrenia, hope and optimism should be offered, knowledge about the illness and relevant services should be provided, and the empowerment of our patients should be supported, as these domains have been identified as important to a recovery orientation (Resnick et al. 2004). Lending hope and optimism will also reduce the self-stigma of the affected person (i.e., blaming oneself for the disorder) because increased self-stigma is associated with a decreased willingness or ability to seek help (Rüsch et al. 2009).

In fact, the true scandal lies in the treatment of the severely mentally ill, particularly individuals with schizophrenia. Based on current knowledge, only a minority of these patients receives appropriate treatment and care. Already in 1998, Lehman stated that significant gaps exist between scientific knowledge about the efficacy of treatments and the availability of those treatments in routine practice (Lehman 1998). The Schizophrenia Patient Outcomes Research Team (PORT) provided, in 2009, a comprehensive summary of current evidence-based psychosocial treatment interventions for persons with schizophrenia (Dixon et al. 2010). PORT produced eight treatment

recommendations: assertive community treatment, supported employment, cognitive behavioral therapy, family-based services, token economy, skills training, psychosocial interventions for alcohol and substance use disorders, and psychosocial interventions for weight management. Only a few have been implemented in routine clinical practice settings. This raises serious concerns about access to care, as well as the appropriateness and quality of care that is offered—aspects which lie mainly within our realm of responsibility.

First column (top to bottom): Vera Morgan, René Kahn, Kim Mueser, Sharmili Sritharan, Wulf Rössler, William Spaulding, and Andreas Meyer-Lindenberg
Second column: Richard Keefe, Wulf Rössler, Anil K. Malhotra, Andreas Meyer-Lindenberg, Til Wykes, Richard Keefe, and Sharmili Sritharan
Third column: Til Wykes, William Spaulding, Vera Morgan, René Kahn, Karoly Nikolich, Anil Malhotra, and Kim Mueser

