Chapter 4

Families and patients with mental illness: on the recovery road

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Introduction

This chapter is dedicated, with love, to my firstborn son who will be 50 at the time of writing (2011). He lives in a group home in Jerusalem, Israel, and his remarkable plight shaped my life for 33 years. I wrote this chapter with his approval to disclose my experiences in relation to his mental illness and recovery, and as an informed and involved father as well as an advocate for mental health services for individuals with mental illness and their families.

The chapter is a confluence of experiences over those years—studies, reflections, and learning from many wonderful families of individuals coping with mental disabilities. Few lessons from my personal experience are explicitly mentioned in later sections. I also learned from visits to conferences, clubhouses, and other facilities, meeting prominent leaders of mental health services as well as leaders and members of the consumers' movements. The NGO "Ozma-Israeli Families of Persons Coping with Mental Illness" is represented in several state councils and committees. I have chaired "Ozma" for 11 years, acquiring a good knowledge of organizations and policies in Israel's mental healthcare system (medical and rehabilitative). Some aspects of that system are described below.

Issues which are relevant, and often agonizing, to families are highlighted throughout the chapter. Among post-puberty young people, acute mental morbidity is the most prevalent morbidity, as evidenced by the risk of mortality and the risk of prolonged life-destruction for the patients and their families. Associated with this morbidity is the severe disruption of the process whereby a young person leaves the nuclear family to attain autonomous functioning and to create a new family unit. Reconstituting this detachment process is an essential goal on the recovery road. It requires strong commitment among the caregivers, families, patients, and society at large.

This chapter is organized as follows. It opens with some general observations on the evolution of nuclear families in present-day societies, before going on to highlight the social unawareness and neglect of young people and families in which the normal detachment process fails. Extreme cases of such failure occurs in acute mental morbidity due to deficiencies and gaps in attitude, knowledge, and services. These gaps are discussed in the section "*Gaps in comprehending mental morbidity and disabilities*". Fears, stigma, and families' harsh experience and frustrations are the topics of subsequent sections, and the chapter ends with a consideration of the winds of change in mental health, rehabilitation, and recovery.

Quo Vadis family

> All happy families look alike, each miserable family is miserable in its own way.

This quip opens Tolstoy's *Anna Karenina*. It is provocative and controversial, and conveys the message that fictional figures and plots can achieve a deeper understanding of human misery than systematic sociological study. However, misery, pain, and sickness usually entail a huge waste of human faculties and energy. Contrary to some claims, deep depression is antithetical to human creativity. Recovery from misery, from physical and mental illness, of patients and their families deserves thorough medical and social research.

We all understand what a family is. Or do we? The concept carries emotionally loaded connotations and an ambiguous social definition. Traditionally, the definition of a family ranged from nuclear (proximal) family to extended family, village community, or a tribe, which played a very significant social role. However, across the globe extended families are fading away in the wake of huge waves of urbanization. These waves have swept across western countries since the dawn of the industrial age. In recent decades, they have swept across billions in Asia, South America, and Africa. The pendulum has swung all the way toward the nuclear family pole. Social organization has lost hierarchical structure. It has evolved into a flat structure which I shall call "OFM

The origins of the family structure are traced to evolutionary advantages (see Figure 4.1). It gives a better chance of survival and the upbringing of descendants. These advantages persist in modern times. In most countries, the nuclear family relationship became a legal entity. Parents (and spouses) have legal rights as well as legal and moral duties.

Nuclear families are the atoms, the smallest socio-economic units, in the modern western social organization, and are also becoming dominant in the developing countries. Typically, each unit consists of one or two parents raising a few children, sharing expenses, and living together in a city flat or a suburban house. Every developed nation and many other nations, large and small, consists of millions of these units. Moreover, in recent decades there has been a trend for western children to remain in their nuclear family home for longer, well beyond the age of puberty, due to longer schooling, education, and job training, and due to a shortage of job opportunities and available housing. In Italy, the state imposes economic sanctions on young people who remain for

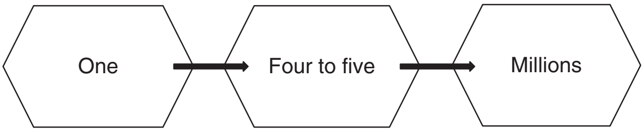

Fig. 4.1 One-Family-Multitude Structure.

too long in their parents' home. This sociological phenomenon, which is very prominent in Italy, puts a heavy burden on the family with disabled offspring, and appears to disrupt rehabilitation and recovery processes of both the family and the disabled individuals (Warner, 1998).

How does this OFM structure evolve? Like biological cells, a crucial event in its life cycle is its division process directed to the creation of a new cell or cells. An analogous event occurs when children are ready to leave their parents' home and embark on creating independent links to wider society and their own family cell.

A successful detachment process, in which the torch is passed to a new generation, is a crucial moment in the family life cycle. There is a tinge of sorrow on the parents' part. However, for typical families, these are (and should be) the happiest moments, signifying success in their "evolutionary mission", irrespective of the ensuing connections between the parties.

One has to acknowledge that there are arguments, from many sides, that believe that assuming there is such a thing as a "typical family" is an unrealistic ideal. Indeed divorces, desertions, poverty, sickness, and disability disrupt many families. The cultural gap between young people and their parents seems to be growing wider in the Internet and social networking generation. However, the nuclear family persists, both materially and legally, as the basic socio-economic unit.

It is interesting to recall an experiment that was conducted for a few decades in the twentieth century in the *kibbutz*—the cooperative settlements in Israel (Rabin, 1986). From infancy, children did not live (and did not even sleep) in their parents' homes, but rather in children's kindergarten, schools, and dormitories, monitored by their instructors. Their main psychological deficiency, which was reported in several studies, was the correlate of deprivation of parental affection, which is claimed to have contributed to an outbreak of psychiatric disturbances (Rabin, 1986). In a nuclear family, the child usually has to compete for affection only with his or her siblings. In a children's society such as that of the original kibbutz, he or she has to compete with many other children for affection. The few lucky ones endowed with charm, beauty, sporting or other social distinctions usually receive all the popularity and praise from their instructors and peers.

More ominously, dictatorial regimes in the twentieth century (or earlier, as illustrated by Savonarola in Florence) established obligatory state youth movements, with military-type discipline, and young people were encouraged in many such cases to spy on (and act against) their families. There were many dire consequences of this practice. During the "cultural revolution", youth bands in China, acting to conform to the will of a dictator, caused the death and suffering of millions of their own family members. In Nazi Germany, during 1939–1941, the state medical authorities killed several hundreds ofthousands of disabled children and young people (many in mental hospitals) under the pretext of an euthanasia policy, claiming that this alleviated the burden and suffering of their nuclear families and the burden of "useless persons" on the national resources.

In present-day welfare societies, family laws, social, health and education services all put (or should put) great emphasis on preserving and strengthening the nuclear family structure. However, there is insufficient awareness of, and too little assistance given to, the young people and families who experience difficulties in detaching to form a new cell. In particular, insufficient help and support are given to families and young people affected by chronic illness or disabilities. Help and support are grossly inadequate in the case of mental disabilities, due to their mystery, complexity, and the deeply ingrained social stigma (and self-stigma) involved in mental disabilities (Corrigan et al, 2011).

Portrait of young people in present-day neo-capitalist societies

Mental disorders affect all ages, causing excess mortality (Brown and Birthwhistle, 1996) and poor physical health (Osborn, 2001), but their impact is most disruptive for the young at the post-puberty age of 16–35 years, which is roughly the second quarter of a human lifespan. Indeed it is estimated that, in most countries, mental disorders are responsible for the deaths (mainly as a result of suicide) of more young people than all somatic diseases combined (Redfield-Jamison, 1999).

Statistically, several factors combine to explain this finding. Modern medicine managed to bring about a very low incidence of serious somatic morbidity in young people, but had little effect on the incidence of acute mental disorders (e.g. schizophrenia and bipolar disorder), which are highly concentrated in the age range 16–35 years. Moreover, the early years of young people with mental disorder are very stormy, and the long-term effects are often devastating for the patients and their families.

As a group phenomenon, I take a bold step and view the young people affected by mental morbidity as extreme cases of a sizeable fallout of post-puberty young people, which is aggravated by the social and economic deprivation among this age group, and by intense pressures on young people in neo-capitalistic societies (Ezer et al, 2011).

Enlightened societies boast of their progressive, generous attitude to children, both legally and emotionally. Children are our darlings. People and organizations are proud to show love, care, and sympathy to their own children and to those of others as well. They generously donate to children's welfare, be those children healthy or sick.

However, an abrupt change of attitude, confirmed in several studies (Ezer et al, 2011), occurs at the age of puberty. Children lose their endearing appearance—boys grow tall, hairy, and coarse voiced, and girls mature to become attractive and even tempting young women. Along with puberty, self-assertion, demands, and expenses on goods and pleasure all rise and become more obtrusive in the eyes of adults.

These young adolescents enter a period of life when there are immense pressures, which are still mounting in urbanized industrial societies, and which have swept most of the world and are characterized by very stiff competition. The pressures arise from sexual drives, gender identity, school load, and competition for social status. They arise from a materialistic "Gold Rush" focused on fashionable clothing, technological devices, and entertainment, and from exposure to smoking, alcohol, and drugs. Reaching the age of 18 years (or 21 years in some countries), young people become officially independent adults. In some countries, young people are drafted into the military (or into national service), which is often a very difficult experience. Many travel on their own, start college or job training, or must work for their living and find a job under stiff competition. They usually leave their parents' home, find a partner, and start a new family of their own. In fact, most of the choices that largely shape the whole course of their future life are made quite early in this period.

The psychosocial and economic deprivations of this age group give rise to serious and troubling questions. The preferential attitudes, care, and benefits given to children are gone. Yet those young people who constitute the future of their nation are now expected to compete and survive, and in several countries they contribute years of their lives to military or national service.

Affluent families do much to help their offspring, and welfare societies also help in various ways by providing free or subsidised higher education and housing loans. However, a troubling question remains. is the investment (private and public) of society in this age group commensurate with its expected yield—that is, the fruits of the investment? In particular, is there enough support to avoid the fallout of a substantial percentage of this age group—that is, young people who fail to achieve productive and satisfying lives that fit their capabilities to a lesser or greater degree? The causes of such fallout are usually health problems and related disabilities (motor, sensory, cognitive, developmental, and mental disabilities, of which the last three account for 70% or more of all disabilities).

The prevailing economic spirit and the concentration of wealth and political power in the hands of a small minority of older adults have led to massive discrimination. Investments to extend and improve the old life of the rich and affluent exceed by far the required allocations to save the large number of young people who fall out and fail to establish decent, productive lives, which they could achieve with suitable help. Such help amounts to a concerted effort to identify and overcome various impediments and disabilities, thus assisting these young people as well as reducing the waste of national resources. The share of investments in the young people's age group is much smaller than their fair share and the expected utility. Consider the health industry, its scientific research, the design and production of medications, devices, and procedures, and the actual medical treatments provided at hospitals and in the community. In western nations, this industry amounts to more than 15% of the Gross National Product (GNP), and in the USA it approaches 25%, including research and development of new medical technologies. The private sector and the public sector both give clear preference to even a slight extension and amelioration of the lives of older people, apparently because financial resources and political power are mostly concentrated in the hands of older individuals (indeed a minority of these, but this minority has a decisive influence).

A recent editorial published in the journal *Nature* (Anon., 2010) claimed that "Biomedical research continues to use many more male subjects than female in clinical trials. The unintended effect is to short-change women's healthcare."

The same holds if the term "young people" is inserted in place of "females", and the term "older people" in place of "males", and the explanation is similar—money and influence.

Strong affirmative actions are required to redirect social and medical investments in favor of the young post-puberty age group in order to lower the percentage of fallouts, including redirection of medical and pharmaceutical research investment (as children and adolescents have long been largely excluded from clinical, and particular psychopharmacological, research). In relation to mental morbidity it implies:

(1) allocating a fare share of the public health budget to mental health (in Israel it is only 5%, compared with 10% or more in western countries)

(2) augmenting the rehabilitation resource and programs to patients and their families.

The case of mental morbidity and associated disabilities is extreme in its difficulties, due to the high incidence among young people, and the wide gaps in comprehension, treatment, and attitude, which are discussed in the next section.

Gaps in the comprehension of mental morbidity and disabilities

A health–sickness framework has many facets, including scientific, social, ethical, legal, and economic ones. Holistic views of health in living creatures, and in human beings in particular, are both noble and useful, and have conformed to medical traditions since ancient times. However, mental health occupied a singular position, with salient gaps between it and the somatic health–sickness framework.

The scientific gap

Conventional medicine has, since ancient times, been the main method of treating sickness and malfunction in living beings and of helping them recover. In modern times, western medicine has been scientifically based on biology and pharmacology, on methodological experimentation, and on extensive and sophisticated instrumentation, tests, and diagnostic tools. The etiology or at least pathology and pathophysiology of most somatic diseases is fairly well understood.

Mental medicine has always lagged behind somatic medicine. There are ample (interrelated) reasons for this gap. The brain and nervous system, especially the human brain and its cortex, is by far the most complex organ. How brain events affect body actions and mind states is still largely unknown. Animal experiments to investigate mental disorders are problematic both epistemologically and ethically. Resources and funds (per patient) allocated for the study of mental disorder were, for a long time, much smaller than those for somatic sickness: “$170 per cancer patient, $150 per heart patient, $7 per mental illness patient” (Weyden, 1998, p. 47).

The Freudian revolution and subsequent trends in clinical psychology have created new ways of understanding and shaping human behavior. However, it is not clear, and quite a controversial issue, whether it contributes to closing the gap in understanding the neurological basis of mental disorders.

The diagnosis of mental disorders is now based on professional manuals, particularly the *International Classification of Diseases and Related Health Problems, 10th Edition (ICD-10)* in Europe and elsewhere, and the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (Text Revision) (DSM-IV-TR)* in North America. The manuals rely only to a limited degree on objective, measurable signs. Psychiatric diagnosis relies on observations and reports by the patient, their entourage, and professionals. The manuals present the perception of an objective diagnostic process organized as an algorithm which has the form of a decision tree, but in many cases the psychiatric diagnostic decision is ambiguous.

Yet treatment should be based on the correct diagnosis, and conform to the individual patient's idiosyncrasies. The ability to select a suitable medication and/or other treatments is the essence of the psychiatrist's expertise. The inherent ambiguities, the diversity in patients' idiosyncratic reactions, and the serious side-effects of many psychiatric medications require extensive experience and learned judgment.

It is generally believed that psychopharmacological treatment, with all its problems and side-effects, has clear advantages over non-treatment. There are vociferous opponents, often followers of scientology, who strongly object to any form of psychiatric treatment. Others claim that the use of medications is inevitable during crises, such as psychotic states, but should not be continued on a long-term basis. Yet it is evident that relapses of psychotic conditions or other serious mental health crises can cause severe and irreversible damage, and possibly even physical damage to the brain. Avoiding relapses and promoting remissions of the mental disorder are essential ingredients of an ambitious medical and social program to enhance recovery in mental disorders.

The social attitude: the kingpin gap

Public awareness of the extent and severity of mental morbidity has always been low and inaccurate. However, in several western countries (the UK included), health authorities now acknowledge the heavy load of mental morbidity as being "the twenty-first-century plague". National programs have been instituted, with an emphasis on the treatment of clinical depression and anxiety, which are the most common psychiatric disorders, affecting people of all ages.

Stigma, concealment, guilt, shame, and blame engulf patients with mental disorders and their families (Corrigan et al, 2011; Marsh and Johnson, 1997). Nowadays, cancer is no longer associated with the concealment and stigma that were prevalent in the past. The social attitude to AIDS is also improving. However, in relation to mental disorders, the gaps are still wide. The irrational fears that feed those gaps and the shame and blame attached to them are discussed in this chapter.

Ethical and legal gaps that cause agony for families

The question of ethics in medical treatment dates back to the Hippocratic Oath. In recent decades, it has moved forward in great strides. Patient rights are now formulated in special laws, and healthcare practice has lost much of its traditionally paternalistic style, and instead seeks full disclosure and maximal cooperation within the "magical care triangle" of professionals, patient, and family. Internet access in the information era has boosted this positive development.

However, mental medicine is lagging behind here, too. Psychiatry and clinical psychology falter to a large extent on two issues which create much agony for families:

many mentally ill patients object to treatment, or neglect it (non-adherence)

medical secrecy—without the patient's explicit consent, disclosure of information to families and medical and social agencies is blocked. The doctor's loyalty is supposedly pertinent strictly to the patient.

The first issue is a serious hurdle, encountered less often in somatic medicine. Indeed, many countries have enacted special treatment laws for mentally ill patients. A central focus in these laws is specification of the medical or social conditions (imminent or non-imminent risks) under which compulsory treatment and/or hospitalization is required. In several countries, only a judge is authorized to issue such commitments. Other countries or states have decided not to distinguish between the medical responsibility and the commitment authority, both of which reside with psychiatrists (unless a criminal act is involved). The patient can commonly appeal to a committee, which includes a judicial expert. The input of families must be heeded and their standing secured in all commitment and release procedures, as families are a prime target of the risks!

The second issue is information disclosure and treatment cooperation. Medical confidentiality is not an absolute imperative, but rather is aimed at defending the patient and avoiding harm to their job opportunities, social connections, insurance acquisition, and similar rights. Due to the prevailing stigma, this is indeed more serious in the case of mental disability. In addition, medical confidentiality respects patient choices about disclosure, or lack thereof, inrelation to their personal health information. On the other hand, non-disclosure of severe mental disorders and treatment details to families and other medical or social agencies is risky. It may cause harm to the patient, their relatives, or others.

Usually, the patient's family is well aware of the mental disorder, and is dedicated to the patient's care and well-being. It is arguably a rare situation when relevant medical details can be used by the family to harm the patient. It could be argued that the rule and practice should be that the family is entitled to obtain full information, unless the caregiver can explicitly justify non-disclosure. This rule applies to information essential for family doctors, hospital doctors treating the patient for somatic reasons, and government agencies (e.g. firearms permits or driving licenses). If there is any doubt, legal and ethical deliberation can and sometimes should be used.

Gaps in service provision and economic discrimination

In several countries, with or without universal health insurance, the mental health services (hospitals and community clinics) are operated as a separate system, outside the somatic medical services. This is medically inconsistent and operationally inefficient. Mental morbidity is positively correlated with high somatic morbidity, and vice versa. Yet few countries, including Israel, maintain separate systems. In Israel, the legislation for merging the mental medicine services with the somatic medicine services has been stalled for many years (Shamir, 2003, 2006; Gleid and Frank, 2009; Imsle, 2011; Levav, 2009; Druss et al., 2011; Shamir, 2010, personal communication).

Separate systems involve massive discrimination against mental health in terms of resources. The influence of mental healthcare advocates in the public arena is quite weak compared with the advocacy and pressures for somatic medical resources. Furthermore, private insurance contracts exclude or place heavy restrictions on clients with a history of mental morbidity. In response to this, some nations, such as the USA, have enacted parity laws forbidding insurance companies to discriminate against clients with mental morbidity.

Separate systems also feed the social stigma. If mental and somatic medical services are provided under the same roof, in the same facilities, the social stigma that is engulfing mental morbidity will subside. It will be perceived in its true perspective like other maladies—grave but not diabolical.

The irrational fears that feed the stigma

At the climax of the Jewish Day of Atonement, the somber prayer "Netane Tokef" is chanted, stating that fasting, praying, and charity (purposeful human activities) can take away the hardship of God's sentencing for the coming year (but not the verdict itself). A major hardship of sickness and disability occurs when it takes over the entire life and existence of the affected individual. Often his or her struggle to overcome the disability is to no avail, because societal stigma is primarily responsible for this hardship (e.g. by labeling the person as schizophrenic or as first and foremost mentally ill).

Whereas people show pity and extend sympathy toward blind individuals, cancer patients, and many other physically disadvantaged people, the prevalent altitude toward the mentally ill patient is fear of possible violence, repulsion, and a tendency to treat the patient as an outcast. Mentally ill patients are the veritable "miserables" of the modern era. Understanding this fear of violence, its extent, how to control it, and how to overcome unfounded fears and prejudices is a complex issue of prime importance.

An analogy with the fear of flight, flight accidents, flight risks, and flight safety is illuminating. Being carried in the air by a heavy vehicle, and trusting ingenious engineering based on laws of aerodynamics which most people do not understand, is a very unnatural situation over which the person has no control. Fear of flight and air accidents is not abated by solid statistics which demonstrate that the likelihood of being involved in a flight accident is much less than that of being involving in an accident when traveling by car, in a train, or on a ship, or even during a pedestrian walk. Plane accidents, even minor ones, are conspicuously reported in the television and newspaper media. Flight safety requires good engineering and special attention to the risks involved in take-off, landing, and traffic control of air space, and more recently in airport security checks.

Likewise, solid statistics show that the overall risk of violent behavior by a person classified as mentally ill is lower, and definitely not greater, than the population average. Moreover, the high-risk situations can be anticipated—patients relapsing into psychotic states can become violent due to imperative auditory hallucinations ("command voices") or paranoid perceptions. Violence shown by people with serious mental illness towards strangers is rare. It is mostly self-directed, as in suicide attempts, or directed toward the person's family or toward persons who are providing care for the patient. Prevention involves proper and timely risk assessment and treatment.

Whereas criminal violence should be punished in order to deter potential criminals, to create stronger cognitive boundaries and warning signals in their minds, violence in the case of psychosis should be addressed through medical treatment, in order to prevent such psychosis-induced violence in the future.

Unfortunately, many sensational crimes are routinely associated with mental illness, even if this association is not evidence based. This dire situation creates gross injustice and damage, boosting the social stigma involving a multitude of people who have mental illness. A thorough re-education, focused on schoolchildren, media reporters, and politicians, among others, may change and ultimately eliminate this dire situation. Well-informed awareness of mental disorders should be fostered in the public, along with emotional sensitivity to the plight of individuals who are coping with mental disorders—and their families.

Miserable families: the vicious circle of guilt, blame, and shame

In many ways, families who are affected by mental illness suffer differently from families who are affected by infirmities from infancy (e.g. autism or intellectual retardation), or by severe chronic somatic illness. The "objective burden" of mental illness on the family is evidenced by a serious, sometimes catastrophic disruption of normal family functions and of the family's economic and social foundation. The "subjective burden" has been described as follows:

> …most family members experience a powerful grieving process as well as numerous intense emotions, including shock, disbelief (and denial), anger, despair, guilt (blame), anxiety and shame.
>
> (Marsh and Johnson, 1997, p. 3; Hasson-Ohayon et al, 2011)

The emotions are intense and continue on a rollercoaster ride as the illness develops, particularly when the illness erupts in young people after a relatively normal childhood (which is quite typical of mental illness). The quoted article, and other studies, discuss these various emotions at length. Here we focus on guilt, blame, and shame—distinct hardships engulfing mental illness.

Professionals used to put the blame on families, as if the families had instigated mental illness. Even since the concept of the "schizophrenogenic mother" was abandoned, society still sometimes puts the blame on the upbringing from the parents, or perhaps on physical and emotional maltreatment. Family members are driven to put the blame on each other, or feel guilty and shame themselves. The tragedy is heightened when the sick patient him- or herself believes (or is made to believe) that such maltreatment is the rational cause of the mysterious, irrational, inexplicable malady and its strange symptoms, even if this belief has no factual basis. Overt or covert accusations of this kind are often made by prominent leaders of the consumers' movement, even those who have become successful professionals. Families feel sad and angered when they hear stories of abuses in childhood without it being stressed that this is not the common or usual cause of the onset of mental disorder.

On the other hand, family members (and strangers) often accuse the mentally ill patient of improper actions or neglect, blaming them for the devastating symptoms of the mental disorder, which are beyond their control.

Thorough educational programs for all of the parties involved are required to break the vicious circle of guilt, blame, and shame that engulfs mental disorders. As a preventive measure, education in schools and in family homes could promote awareness of the possibility and risks of mental disorders. Neutralizing the guilt, blame, and shame in young people opens the way to adaptive help seeking from supports—both informal (parents and friends) and formal (professional care providers). It may decrease the risk of suicidal thinking and suicide attempts, which have a high prevalence in this age group.

Starting in schools and family homes, the thorough re-education of the general public about mental health and mental disorders can gain momentum. Here we focus on the interactions of families and patients after the onset of the disorder.

Several studies have demonstrated the advantages of major efforts to control and reduce the intensity of expression of unhelpful emotions such as hostility, anxiousness, and even over-involvement. In families with lower levels of such expressed emotion, there are fewer relapses of psychosis and a greater likelihood of remission (Leff and Vaughn, 1985). Many families learn this from long and hard experience. Targeted psychoeducation for families, usually in groups, should be easily available and is strongly recommended. However, with regard to guilt, blame, and shame, the goal is not to reduce these feelings but to eradicate them. This is the topic of stigma-centered support groups, which may be shared by patients and families.

Family support groups have been found to be very effective in creating strong empathy, because each family realizes that other families have had similar difficult experiences, feel the same emotions, and have trodden the same difficult path of coping with mental illness within the family. Also, experienced families are very effective in convincing "new" families to seek treatment, rehabilitation, and social help, thereby augmenting professional services.

Personal experience

There have been many reports published of family members being highly involved in the experiences of people with mental disorders (e.g. Weyden, 1998). John Nash's biography *A Beautiful Mind* (Nasar, 1998) gives a detailed description of how his mother, sister, and wife sustained help.

From my personal experience over a period of 33 years I shall briefly highlight some of the issues.

1. *Women, especially mothers, carry the main burden.* The hospitalization of my firstborn son for 3 months at the age of 17 years happened 5 years after his mother, my first wife, had died, and I was left for about 12 years as a single parent with three boys to bring up. Otherwise, my wife would have carried the main burden, as is usually the case in most families. Many fathers find refuge (more or less) in their professional career, but most of the activists in family organizations in all countries are women.
2. *Many years wasted, due to faults of the system and my own.* For 8 years between his first and second hospitalization my sick son lived with us. Heroically, he managed to finish secondary school (by external examinations). He tried many directions of work, from simple physical work to short professional courses, but everything failed because of the meager support by the medical system, the total lack of rehabilitation programs, and a lack of determined family help. He suffered from the side-effects of the first-generation antipsychotic drugs, and hated taking them. During his third prolonged hospitalization, the Leponex (clozapine) drug treatment started, and continued, with apparent success. Each week he came home

for prolonged weekend vacations, and he finally moved to a newly founded group home (hostel), where he has been living for the last 14 years.

a. Similar stories of wasted years were and still are quite common. The most urgent task of the families, the medical system, and the rehabilitation system is to act as soon as possible during the early stages of the disease and thereby avoid the terrible cost of wasting precious time. It is the primary mission of families, NGOs, and civil rights groups to campaign for this goal in the public arena.

b. *Leaving hospital for the hostel and rehabilitation.* This event, which took place 15 years ago, definitely marked the most significant improvement in our quality of life. My son's medical condition is stable, and there has been a slow but steady improvement in the "negative symptoms". I have been able to resume my professional work and enjoy a happier family life. The care load is shared with professional rehabilitation staff. During these years I have been engaged in almost full-time voluntary work for the families NGO, "Ozma", which I chair.

c. *Taking moderate risks toward recovery progress.* For several years, the employment arrangements for my son were boring, unproductive, and futile. The rehabilitation staff feared that the pressure of change, which I was demanding, would impair my son's medical stability. Ultimately, the risk was taken, a change was made, and it definitely paid off.

3. *Controlled detachment, promoting patients' independence.* I was convinced by the rehabilitation staff and by extensive reading to avoid intervention and allow my son to have independence with regard to the running of his daily life, his appearance and behavior, how he spends his small income, and his shopping and leisure activities. In his free time he likes to draw, and he also participates in a drama group.

4. *Our social relationship*. This relationship, including the few hours each week I spend together with my son, has become much more rewarding in recent years. He is invited to be with us at holiday dinners and during extended family celebrations.

Winds of change: raising sights and reshaping goals in mental health

The relative lag in etiology and medical understanding of mental disturbances led to channeling of the reformation energy to initiate a breakthrough in the social directions—de-institutionalization, rehabilitation in the community, and novel concepts of recovery—which can be induced and achieved beyond the strict medical arena.

The pressures to reform the ways in which mental healthcare is conducted came mainly from outside the medical profession, from organizations such as the National Alliance on Mental Illness (NAMI) in the USA, and the various organizations which are members of the European Federation of Associations of Families of People with Mental Illness (EUFAMI). Groups of psychiatrists who were dissatisfied with the strict medical procedures created the World Association for Psychosocial Rehabilitation (WAPR), which recruited consumers and families to its board. It enjoys strong standing in developing countries, most prominently in India (Saraceno, 2009).

In Israel, the NGO "Enosh", founded by families in 1975, was a pioneer in launching rehabilitation services for mentally disabled persons. Organizations devoted solely to advocacy for the medical and rehabilitation needs of the mentally disabled were founded during the 1990s by consumers and families ("Ozma").

Rehabilitation in the community of patients who suffer or have suffered from severe mental illness has, in recent years, been the most significant development in relation to mental health. This is true for developed countries, for Israel, and even more so for developing countries (such as India), which suffer from an acute shortage of psychiatrists and psychologists.

Rehabilitation: the indispensable partner

De-institutionalization of the care of mentally disabled people is practically impossible without a large-scale plan for rehabilitating these individuals in the community. Beyond the human aspect of individual well-being, it amounts (or can amount) to a deep change of social attitude—from seclusion of these people and ostracisation to acceptance and integration.

Is psychiatric rehabilitation similar to physical rehabilitation after a serious physical trauma, such as a heart attack or a stroke? The answer is yes and no. Both processes work on restoring functions that were disabled by the sickness. The main difference lies in the involvement, control, and guidance of the medical staff during the process. This is commonly substantial for physical rehabilitation, yet it is often minimal for psychiatric rehabilitation (at least in some jurisdictions, particularly outside of North America and Western Europe (Druss et al., 2000)).

Psychiatrists are sometimes involved in determining the level of mental disability that makes the person eligible for a disability allowance (and a "rehabilitation package" in Israel, which is 40% disability or more). The Israeli Rehabilitation Law (2000) explicitly defines rehabilitation as "a process which takes place in the community" (Israeli families lobbied through their NGO "Ozma" that the term "community" should exclude "rehabilitation departments" in hospitals). Indeed, staff who are practicing rehabilitation convey a clear message that the sickness should be set aside and that they should focus on the functioning of the person and the problems of housing, employment, leisure activities, and social relationships. These are the explicit constituents of the Israel law, which is internationally hailed as progressive and ground-breaking. A decade after its implementation in Israel it is rated as a remarkable success, and has been highlighted by an International Workshop (2010).

An estimated 40% of the eligible candidates in Israel were examined by the regional government-operated "rehabilitation package committees". More than 50% of those candidates received services provided by private-market companies and non-profit organizations. The government pays the cost of each individual package. Over a period of 10 years the total rehabilitation annual budget increased by 500%, and it continues to grow at a moderate rate.

Studies that have already been conducted (more extensive ones are planned) highlight the remarkable human and social contribution (International Workshop, 2010). Moreover, the contribution to the national economy outweighs the cost of the rehabilitation investments, in terms of increased productivity of the families and the patients, large savings in medical expenses, a reduction in psychiatric hospitalizations, and a substantial increase in job opportunities in rehabilitation services for social workers and paramedical staff.

Accumulated experience indicates that effective rehabilitation exhibits a definite bootstrap effect. The first steps are the most difficult, but as the walls start to tumble, further advances become easier. Indeed, this bootstrap effect motivated practitioners to raise their sights and introduce recovery goals. The practice and experience also led to flexible and dynamic progress in the various aspects of rehabilitation.

In housing, the transition is from group homes to a “supporting community” model, where a cluster of several rented apartments in the same neighborhood are supported by a central facility, which often contains a hostel for those who are still experiencing difficulties living in a rented apartment.

In employment, the transition is from protected factories with low-grade work and poor salaries to supported employment in the free market (or the civil service), and to food and coffee houses where the workers are also responsible for the marketing, accounting, etc.

In leisure, the transition is to activities that present increased challenges in terms of learning and performance, such as various sports activities, drama, art and music, or various skill acquisitions, with a preference for joint activities with healthy individuals or people with other kinds of disabilities.

The clubhouse movement was the forerunner in progressive rehabilitation. Its ideas were sound, but its rules were found to be too rigid in many cases.

Improvement in the quality of life of the patient as a result of rehabilitation (which is often quite dramatic) leads to a parallel improvement in the life of their nuclear family. In the stormy sea of mental morbidity they ride the same boat. Moreover, a new rider joins and stabilizes the ride—the rehabilitation crew. Unlike the medical crews, their contacts with the patients in the community are intensive, sometimes even occurring on a daily basis. The desired triangle of care (i.e. “family, patient, and professionals”) achieves concrete realization. Many families express their great relief when the responsibilities of caregiving are truly shared. They contrast them with the burden of anxieties and frustrations when the patient is heavily dependent on his or her family, deprived of employment, decent housing, and meaningful social relationships, and exposed to frequent or prolonged hospitalizations (Spaniol et al., 1992).

One successful innovation of the Israeli law has been the establishment of counseling and support centers for eligible families. By 2011 these centers were operating in 10 cities. The centers provide several services, including support groups for family members and individual counseling. They help families to become effective partners in caregiving and to take part in advocacy and stigma elimination.

The recovery road: a strong commitment of all parties

Recovery in relation to mental morbidity, as a practicable and achievable goal, together with exploration of its meaning, been gaining momentum in recent years. It was a central theme in the International Workshop (2010).

The notion of recovery from chronic or persistent illness appears in two forms:

1. *objective*—termination of symptoms of illness and recovery of normal functions, such as self-care, employment, and social relationships
2. *subjective*—termination of the despair and of the desolate situation, and the revival of hope and purpose in life.

Both forms merge into one, namely regaining control of one's life as an adult.

In somatic illness, the subjective recovery is often a corollary of objective recovery—that of the termination of the physical suffering. For mental disorders, the subjective notion of recovery is an essential primary ingredient, because the spirit (or "soul" in several languages) is often a primary victim of these disorders.

The dual form of recovery applies to families as well, with revival of hope and purpose on the one hand, and recovering the normal functions of each family member in terms of their work and career, childrearing, and leisure activities on the other.

For a long time, professionals set their sight on remission of serious mental illness. The pharmacological and other treatments seemed to control some symptoms and to prevent relapses, but had little effect on the patients resuming their normal daily functioning. More extensive studies have shown that a sizable proportion (around 40%) of seriously mentally ill persons, including those with a diagnosis of schizophrenia, achieve recovery without treatment or after short-term treatment. Moreover, as experience in rehabilitation has accumulated, the sights of the "care triangle" (professionals, patients, and families) were set on a higher goal—a walk on the recovery road (Anthony, 1992).

Setting recovery as an attainable goal in relation to mental illness is a bold program. Such recovery is not a discrete event in time, but an ongoing process that requires the commitment of all the parties involved. The hurdles to the recovery process should be anticipated. The main hurdle is the huge delay in acquiring and building the basis for the life and career of the recovering young person. It appears to be proportional to the number of years lost to the illness. The loss and waste during mental illness are often greater than the loss in somatic illnesses. The delay is aggravated by the competitive nature of neo-capitalistic societies. The young person often realizes how far behind they are in comparison with the general population of their age in building social relationships, establishing an economic basis, and gaining a professional education. This may lead to deep frustrations and despair. Paradoxically, despair is more dangerous for those who have achieved more complete rehabilitation and who require less support in housing and competitive (free-market) employment. These individuals often experience a huge gap or disadvantage in comparison with the general population of their age—they feel that doors are closed, and that they cannot cope with the stiff competition.

The walk on the recovery road involves strong commitment by all of the parties involved.

Social commitments

Society has to commit to proper resources and services—medical, social, and rehabilitative. Patients and their families on the recovery road may become more amenable to psychological consultation and support, which should be provided as needed.

Finding and retaining proper employment is crucial for the recovery process of many individuals, as has been observed in many studies (International Workshop, 2010). Affirmative action is needed, giving preference to people with a history of disabilities (of all kinds)—for example, by protecting a certain proportion of the positions in public employment for people with disabilities.

The disability allowances provided by governments when people cannot earn a living should not be cut or curtailed, at least for a while, when they manage to find employment with a decent salary. Curtailing such allowances amounts to a negative incentive to finding work for earning a living.

Families who provide board and lodging for their disabled adult offspring should receive public support and tax benefits. Increased tax benefits should be given to families who invest in rehabilitation services. This saves public money and improves the quality of the services, as people will usually prefer to invest in the better services.

Family commitments to recovery

It takes considerable and persistent effort for affected families to extricate themselves from the dismal state outlined earlier.

Family recovery essentially involves the regaining of the normal functioning of each family member—this includes their work and professional career, upbringing and education of children, and social relationships. Often the process requires help on an individual basis and/or a support group for families, and social aid.

In addition to its intrinsic value, family recovery contributes to the patient's recovery by aleviating the feelings of guilt that he or she may harbor for disrupting family life, and it prevents excessive exploitation of the family's material and spiritual resources.

A crucial issue is the relentless effort to reduce the dependence and overprotection of the patient. This is easier said than done. In many cases, the volatile medical situation continues for many years, with occasional relapses into psychotic crises. More typical are cases where, after many years, the chronic illness subsides but the patient lacks employment, is unable to earn a living, and their social integration is meager. Even if the family provides financial support (which is often the case for healthy offspring), the patient should run his or her own budget and life schedule. This may seem risky to protective parents, but in the long run it is beneficial for recovery.

On the social side, every effort should be made to ensure that the patient lives outside their family home. Scheduled weekly reunions with joint activities, such as cooking together, sport, or walking in the park, seem appropriate. Inviting the patient to holiday dinners and family events is essential, as is allowing the patient to accept or decline such invitations without any offense being caused.

What will happen after the parents have died?

Parental death causes families much anxiety, and remains an unsolved problem. How should one word one's will? Is it necessary to appoint a guardian, at least to oversee property and capital inherited by the patient? Is it wise to give the task to a brother, sister, or other relative? Or should one perhaps nominate an organization that provides rehabilitation services to the patient? The legal and social issues are beyond the scope of this chapter, but the guideline should be as follows. do not seek to overprotect, trust that the patient is on a recovery road, and give them the maximum possible control of their life.

Joint commitments of the "care triangle"

For patients, families, and professionals, the joint commitment is to revive and maintain the sense of value and self-respect of the patient. This sounds like an obvious statement in the field of human relationships, but it is crucial for mental patients, in whom the sense of value is one of the main victims of the malady. The patient's commitment to adhere to the medical treatment and to the rehabilitation practices, and to be productive in employment (or in other ways) should receive praise and gain the encouragement and high esteem of family, professionals, and others.

Conclusion

Mental morbidity affects all age groups, but the impact may be greatest on young people post puberty. In present-day societies, young people are subject to intense pressures, and too many of them fall behind. Those afflicted by mental illness are the extreme cases of this fallout. In the prevalent neo-capitalist system, private and public spending is (contrary to the logic of future utility) biased against young people. Resource allocations to curb fallout among young people are too small.

Nations should redirect resource allocations in favor of the young generation. To curb mental morbidity, equitable and adequate resources for medical services and rehabilitation programs are essential. Time is critical. Insist on determined outreach to patients and their families, close to the outbreak of the malady, overcoming denial, shame, and guilt. Public education programs are in dire need, to close the social, legal, and discriminative gaps which haunt mental morbidity, and to eliminate the engulfing stigma.

The burden of coping with mental morbidity lies heavily on families. Several sources of distress have been outlined, along with ways to remedy them. Foremost among these are:

honest cooperation between the parties of the "care triangle", namely patients, families, and professionals

generous rehabilitation packages for disabled patients, coupled with extensive support for their families.

Strong commitments of society and of the "care triangle" will promote remarkable progress on the road to recovery for patients and their families.

Hopefully brain research, vigorously financed and pursued, will close the scientific gap, so that mental morbidity will regress at the same pace as somatic morbidities, especially among the young generation. Amen!

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